

SRI International

Kansas Early Intervention Longitudinal Study

SERVICES, CHILD AND FAMILY OUTCOMES, AND PROVIDER CHARACTERISTICS IN KANSAS AT THE END OF EARLY INTERVENTION

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CHAPTER 1

INTRODUCTION

In 1986, federal legislation (P.L. 99-457) created the Early Intervention Program for Infants and Toddlers with Disabilities, now Part C of the Individuals with Disabilities Education Act, as amended in 1997 (IDEA97). Through this legislation, states have received funds to build coordinated, interagency systems of early intervention (EI) services. The years that followed have seen steady growth in the number of infants and toddlers served through Part C, increasing from an estimated 128,000 in 1988 (U.S. Department of Education, 1990) to 230,853 in 2000 (U.S. Department of Education, 2002). To meet the need for more and better information about Part C and its participant states, the Office of Special Education Programs (OSEP) of the U.S. Department of Education commissioned SRI International (SRI) to conduct the National Early Intervention Longitudinal Study (NEILS). NEILS is following a nationally representative sample of children and families who were recruited into the study from September 1997 through November 1998 as they entered EI for the first time. Kansas was one of the 20 states included in the NEILS sample.

In December 1998, the Kansas Department of Health and Environment contracted with SRI to collect data on an additional sample of children receiving Early Intervention (EI) services in Kansas. This supplemental sample, when combined with data from the Kansas sample included in NEILS, would allow estimates to be generated for the population of children in EI in the entire state. The study procedures that were followed were identical to those carried out for NEILS. The data collection for the supplemental sample involved interviews with families, service data forms from service providers, service provider surveys, and program director surveys. Years 1, 2, 3, and 4 of the Kansas Early Intervention Longitudinal Study (KEILS) correspond to calendar years 1999, 2000, 2001, and 2002.

KEILS addresses the following study questions:

- Who are the children and families receiving EI services in Kansas?
- What EI services do participating children and families receive, and how are they delivered?
- What outcomes do participating children and families experience?
- How do outcomes relate to variations in child and family characteristics, and the services provided?

A total of 316 families are included in KEILS. In addition to the 68 families in the national study, an additional 248 families were recruited as the supplemental sample. For all of the analyses presented here, data from these two samples are combined. More details on the KEILS enrollment data and findings at entry into EI can be found in Mallik and Hebbeler (2002).

Data Collection

Family Interviews at Entry and at 36 Months

Once a family was enrolled in the study, Research Triangle Institute (RTI), working under subcontract to SRI, conducted a telephone interview with a family member able to answer questions about the child and the services provided for the child. These interviews could be completed up to 4 months from the date of the Individualized Family Service Plan (IFSP). A year after this interview, families whose children were still younger than 36 months, were contacted again for a second interview. The families of the older children were interviewed around the time the child turned 3. Some of the data presented in this report are based on

information collected through the last family interview (conducted about the time the child turned 36 months). The findings are based on those families that had a family interview (or responded to a mail questionnaire) at entry and at the time the child turned 36 months (N=237). Children would be expected to leave EI services when 36 months of age, and the study design called for interviewing the families of all children at this critical juncture. Nearly all (90%) of these interviews were conducted within 3 months of the child's third birthday. For the first interview and the 36-month interview, if a family member could not be reached for the interview, the family was sent a mail questionnaire containing a subset of the questions in the telephone interview. The data from the mail questionnaires were collected at least 4 months after the intended data collection point because the surveys were mailed out after months of unsuccessfully trying to reach the family by phone. Of the 237 respondents, 87% were the biological mother, 3% the adoptive mother, 5% the biological father, and 4% had some other relationship to the child (e.g., adoptive father, grandmother, aunt, female legal guardian).

Service Provider Survey

Findings reported on service provider characteristics are based on a sample of 158 individuals who provided EI services to children and families in the study sample during the first 6 months the children were in EI. At the time of study enrollment, the EI program provided the name and address of the service provider who was most familiar with the child's and family's services. Six months after the initial IFSP, this provider was mailed a form that asked for the names and type of provider (e.g., speech therapist) for every EI service provider who had worked with the child or family during the previous six months. All of the providers identified on this form were mailed a Service Provider Survey and their responses constituted the basis for our analysis of service providers

Because the children had multiple providers and the data are weighted to the population of children in EI in the state, we weighted the data separately for each provider category. Data were sufficient for analyses of four provider types. The data for each of these provider types were weighted so that the results were representative of the children and families who received services from that provider type.

Service Records

Using data obtained from Service Records (SRs), we describe selected characteristics of the EI services provided in Kansas after a child and family's entry into the system and through the end of EI. At the time of enrollment into EI and enrollment into the study, staff at EI agencies were asked to provide the name and address of the one EI professional who would be most knowledgeable about the services that the child and family would be receiving. Frequently, this individual was the family's service coordinator, but he or she could have been any other professional. Six months after the development of the initial IFSP, this provider was mailed an SR form. The SR form asked the provider for several kinds of information about the services the child and family had received in the preceding 6 months. SRs were also collected every 6 months for the 165 children who stayed until the end of EI, which they left at the age of 36 months. Because the data were derived from SRs for children known to have stayed in EI until they turned 36 months, the findings are described in terms of whether any aspect of services were "ever" received over the course of the child's stay in EI. The analyses look across multiple SRs and thus describe the percentage of children and families who "ever" received a service with a particular characteristic. The service data are weighted to represent the population of infants and toddlers entering EI in Kansas in the late 1990s. Because of the nature of the sample selection procedures employed and the weights applied to the data, the percentages and means presented in this report represent statewide estimates. Additional information about interpreting weighted data can be found in Mallik and Hebbeler (2004b).

Data Analysis

All data are weighted, which means that we have applied numerical weights to the raw data. Because of the nature of the sample selection procedures employed and the weights applied to the data, the percentages and means given in this report represent statewide estimates for children who entered EI at 26 months of age or younger.

The percentages and means presented are only estimates of the actual percentages and means that would have been obtained if all children entering EI in the state had been included in the study. The estimates vary in regard to how closely they approximate the true measures. To examine the precision of the estimate, our researchers used a statistic called the “standard error.”

To determine the precision of a particular percentage or mean, the reader can construct a confidence interval for the estimate by multiplying the standard error by 1.96. The result is the range around the estimate within which the true measure would be found in 95 out of 100 samples. For example, as noted in previous findings (Mallik & Hebbeler, 2002), 66.4% of children entering EI in Kansas were male. The standard error of that estimate, 3.8, is multiplied by 1.96, letting us assume with 95% confidence that the true percentage of males falls within a range of ± 7.45 percentage points, or 58.95 to 73.85%. Appendix A sets forth the standard errors associated with the data reported in the tables in the chapters that follow.

This report provides a look at several different aspects of EI in Kansas. Each chapter provides information on data collection, data analyses, and findings related to the topic addressed. Chapters 2 through 7 provide findings. Chapter 2 addresses the characteristics of services over the child and family’s time in EI. Chapter 3 presents descriptive data about the characteristics of the providers who are delivering EI services in the state. Chapter 4 addresses how long children stay in EI. Chapter 5 addresses child outcomes at 36 months, and Chapter 6 addresses family outcomes. The last chapter, Chapter 7, presents findings related to the transition out of EI and provides a summary and conclusion.

CHAPTER 2

CHARACTERISTICS OF EARLY INTERVENTION SERVICES

Providing appropriate services to children and families is the core of EI under Part C of the Individuals with Disabilities Education Act (IDEA97. Researches have found that the nature and structure of EI services vary from place to place in regard to several factors, in part because of differences in EI service delivery that existed before Part C was implemented and in part because states have some latitude in implementing Part C (Harbin, McWilliam, & Gallagher, 2000; Hebbeler, 1997; Kochanek & Buka, 1998; Spiker, Hebbeler, Wagner, Cameto, & McKenna, 2000). Understanding the nature of EI service delivery is of significance at many levels, including the development of federal and state policies to improve services and, ultimately, the results of those services. Describing EI, however, is not straightforward because of its many features. For example, EI can be characterized with regard to type of service (e.g., speech therapy, nutrition service), location of service (e.g., home, specialized center), or provider of service (e.g., nurse, physical therapist), to mention a few critical features. However, as yet, we do not know which EI features are the most important for producing good outcomes for children and families.

An earlier report described the nature of EI services provided to children and families across the state in the first 6 months after the development of their Individualized Family Service Plans (IFSPs) (Mallik & Hebbeler, 2004b). This chapter examines the characteristics of the EI services provided in Kansas over the child and family's entire time with the system.

Data Collection: Service Records

At the time of children and families' enrollment in EI and enrollment in the study, staff at EI agencies were asked to provide the name and address of the one EI professional who would be most knowledgeable about the services that the child and family would be receiving. Frequently, this individual was the family's service coordinator, but could be any other professional. Six months after the development of the initial IFSP, this provider was mailed a Service Record (SR) form, which requested several kinds of information about the services the child and family had received in the preceding 6 months. The SR form was sent to the provider most knowledgeable about the child's services every 6 months thereafter, until the child left EI. The data in this chapter are based on SRs for the 165 children in the study who continued to receive services until 36 months of age. The analyses, which take multiple SRs into account, describe the percentage of children and families who "ever" received a service with a particular characteristic. The service data are weighted to represent the population of infants and toddlers entering EI in Kansas in the late 1990s. Because of the sample selection procedures employed and the weights applied to the data, the percentages and means presented in this report represent statewide estimates. Additional information about interpreting weighted data can be found in Mallik and Hebbeler (2004b)

Appendix A sets forth the standard errors associated with the data reported in the tables in this chapter.

Limitations

One limitation of the study is the potential for bias because of incomplete data. SRI sought to obtain SR information for every child and family from the service providers. However, some providers did not return SRs despite SRI's repeated requests for them to do so. This issue has been addressed to some extent in the weighting procedures; those children for whom SRs were returned were weighted to represent similar children for whom SRs were not returned. Not all SRs were returned for all children who stayed in EI until

36 months. Some of the children for whom SRs were not returned may have differed in systematic ways from other children, and thus the findings should not be generalized beyond those for whom data were provided. Because substantial differences exist within the EI population between children who enter EI at younger and older ages, we emphasize that the data presented here do not represent the entire population of children in EI in Kansas.

The remainder of the chapter addresses the following topics:

- Types and number of services ever received over the course of EI
- Types of service providers that ever delivered services to the children
- Consultation between service providers and early childhood teachers or child care providers
- Types of service settings where services were ever received
- Reasons services were missed.

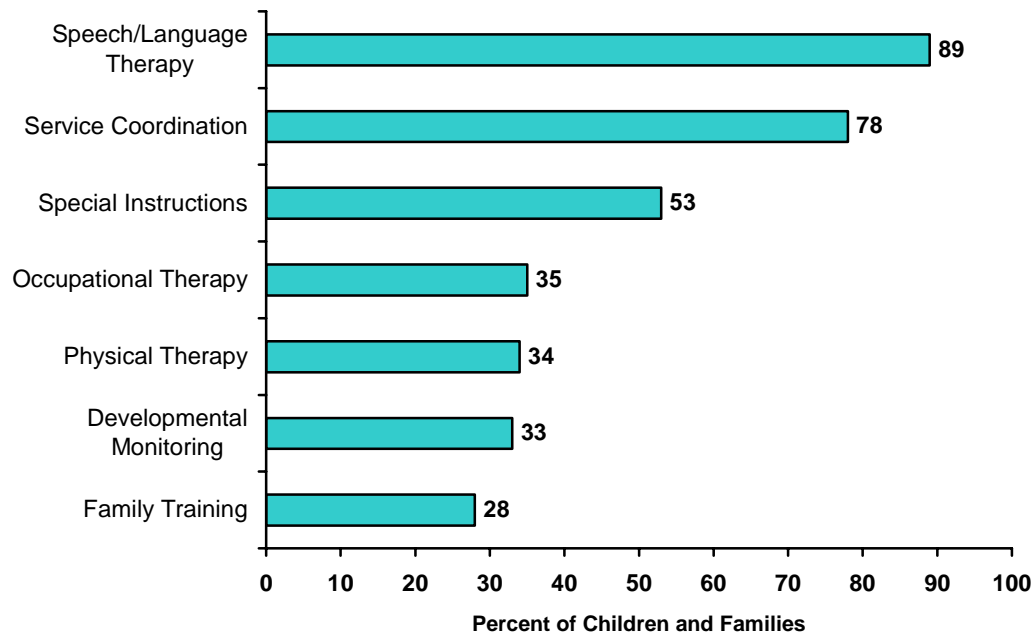
Types and Number of Services Ever Received

Figure 2-1 shows the seven services that were most frequently received by children and families in EI. Speech/language therapy was the most frequently received service: 89% of children were reported to have received this service through EI. Only 78% of children were reported to have ever received service coordination. As explained in the previous report on services (Mallik & Hebbeler, 2004b), this percentage could be less than 100% for several reasons. First, some families may have declined service coordination. Second, these data are based on a long list of services against which the provider checked off all the services the family had received in the past 6 months. Some respondents may not have checked off service coordination because it is not an individualized service like the other services.

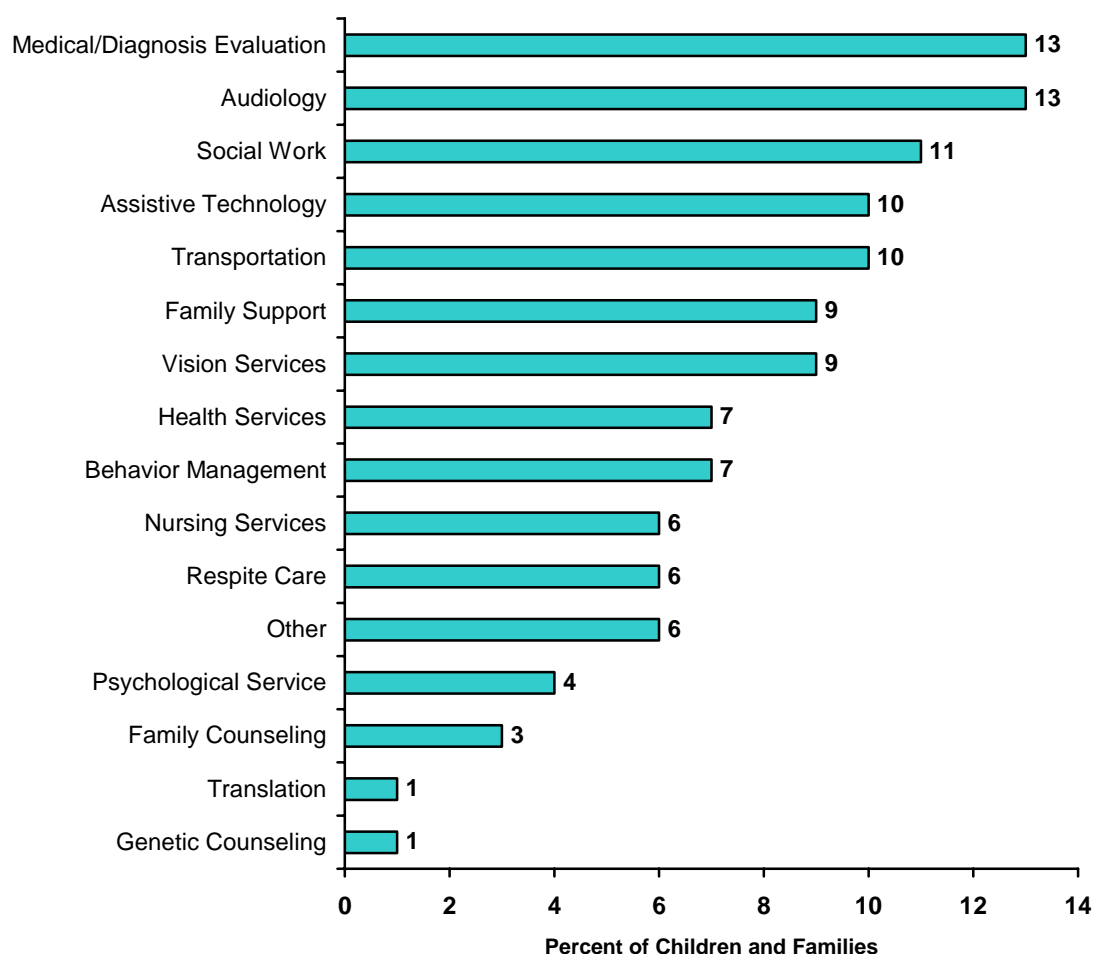
After speech therapy and service coordination, the services most frequently received were special instruction (53%), occupational therapy (35%), physical therapy (34%), developmental monitoring (33%), and family training (28%). A number of other services were received by fewer than 20% of families. Figure 2-2 lists these services, ranging from audiology (13%) to genetic counseling/evaluation (1%), and the percentages of children or families who received them. These findings closely resemble those for the first 6 months of EI (Mallik & Hebbeler, 2004) except that the proportions for services received over the entire course of EI are slightly larger.

In terms of the number of settings in which children and families received services over the entire duration of EI, 44% of children and families ever received services in 1 setting, 46% received services in 2 settings, and 10% received services in 3 or more settings.

Figure 2-1. Children and Families Who Ever Received Each Type of Service (Services Received by 20% or More of Children and Families)



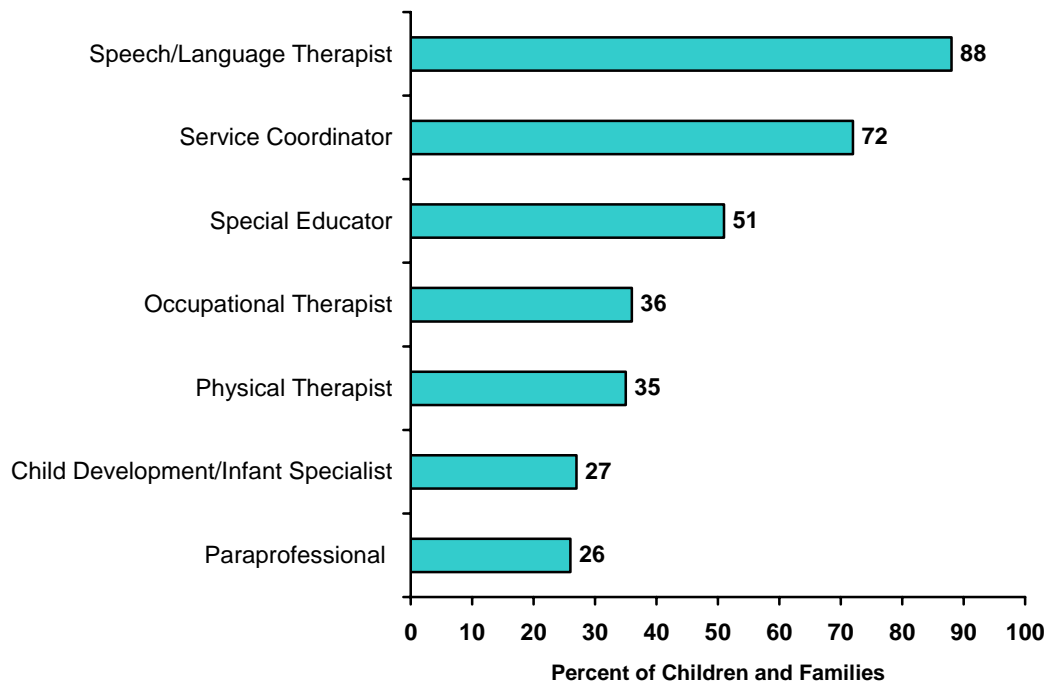
**Figure 2-2. Children and Families Who Ever Received Each Type of Service
(Services Received by Fewer than 20% of Children and Families)**



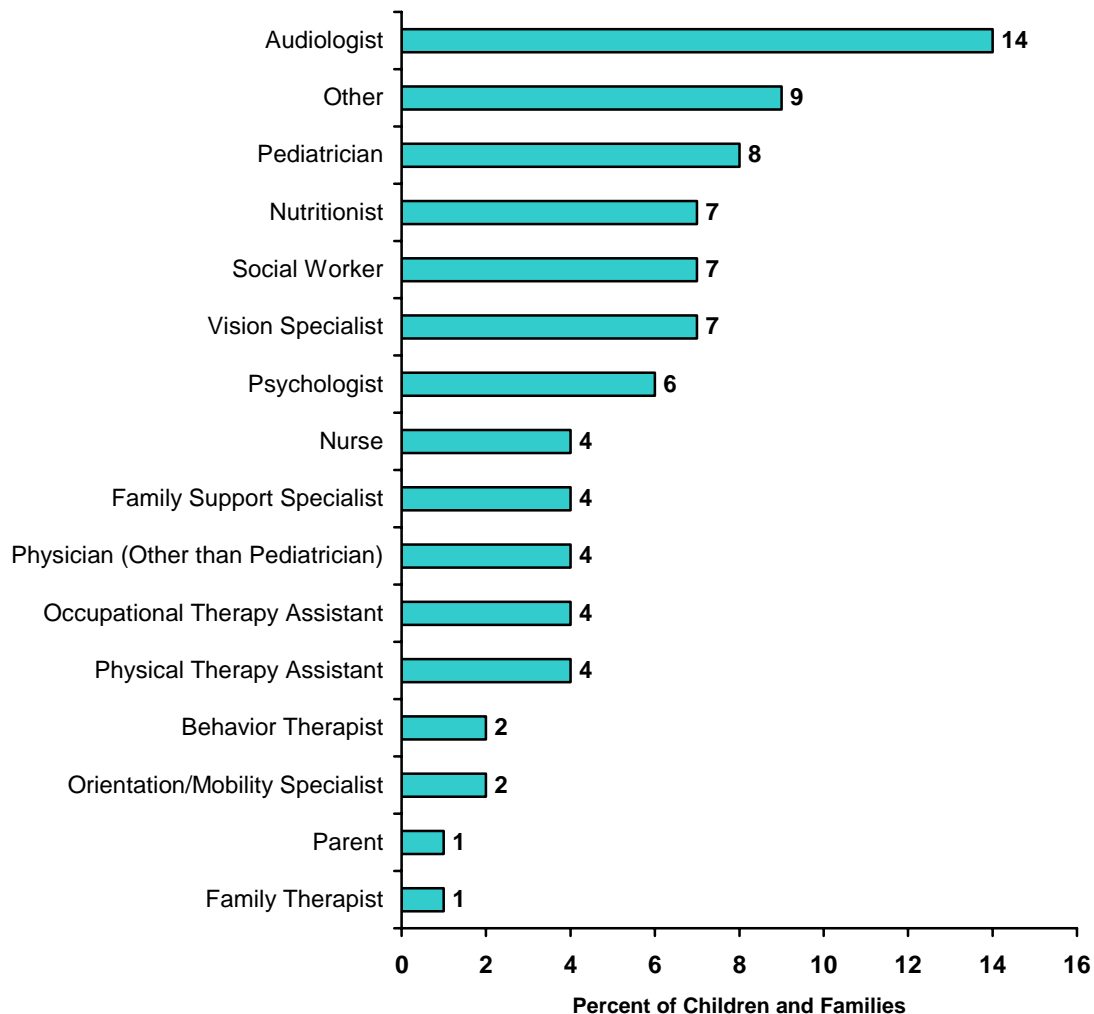
Types of Providers in EI

Several kinds of professionals provide EI services. Not surprisingly, given the large proportion of children who receive speech therapy, the professionals who worked with the largest percentage of children and families over the course of EI were speech therapists (see Figure 2-3). Nearly 90% of children and families received services from speech/language therapists, followed by service coordinators (72%), special educators (51%), occupational therapists (36%), physical therapists (35%), child development/infant specialists (27%), and paraprofessionals (26%). Other professionals also were involved with children and families over the course of EI, but to a lesser extent (see Figure 2-4); they ranged from audiologists (14%) to family therapists (1%); that is, 14% of children and families ever received services from an audiologist, and 1% ever received services from family therapists. These patterns somewhat resemble those in the first 6 months of services in EI (Mallik & Hebbeler, 2002) where speech therapists, service coordinators, special educators, physical therapists, and occupational therapists were the most likely to provide services to children and families in the first 6 months of EI.

**Figure 2-3. Children and Families Who Ever Received EI Services from
Each Type of Service Provider
(Service Providers Working with 20% or More of Children and Families)**



**Figure 2-4. Children and Families Who Received Services from Each Type of Service Provider during the First 6 Months in EI
(Service Providers Working with Fewer than 20% of Children and Families)**



NOTE: "Parent" in the figure above refers to a parent other than the child's own parent

The data in Figure 2-3 indicate that only about three-quarters of families were working with a service coordinator over the course of EI; this may be an underestimate, however, because of the way the data on providers were collected. The data on professionals working with a family were collected for the services provided in particular settings; that is, providers were asked to report on all the professionals who worked with the family in the home, in a center, etc. Because service coordination may cut across settings or be carried out mostly in an office, the service coordinator may not have been reported as a provider for the settings asked about. In addition, some service coordinators may have also served a family in another capacity (e.g., as speech therapist), and respondents may have reported only one role rather than both.

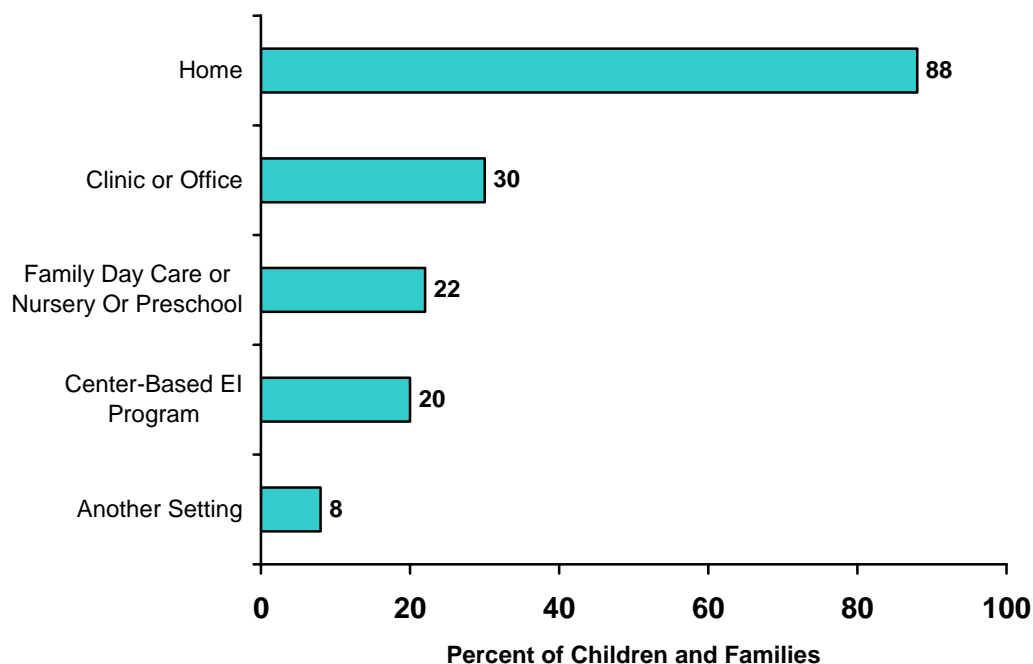
Consultation Between Service Providers

Some models of EI service delivery encourage providers to work in a consultative capacity with other providers. In these models, the child's and family's needs are met by a small number of providers who bring the expertise of other colleagues to bear through the benefits of consultation. In addition, consultation could occur between a therapist and an early childhood teacher or child care provider to assist them in working with the child. The SR form asked which types of providers consulted about the child or family in the previous 6 months. For the entire duration of EI, a speech therapist had been involved in consultation for 87% of children and families. The professionals involved in consultative services next most often were service coordinators (82% of the children and families), special educators (50%), occupational therapists (38%), and physical therapists (38%). A wide range of other types of providers was less involved in consultation, with only 18% of children and families receiving consultation from social workers and only 1% from orientation mobility specialists. The SR form asked whether any EI service provider consulted with a family day care provider or preschool/nursery school teacher about activities or services that he or she could undertake for the child. Thirty-one percent of children and families had an EI provider who consulted with an early childhood teacher or child care provider sometime over the course of EI.

Service Settings

EI services are provided in a variety of locations. The setting where services are provided has taken on additional importance in recent years as providing services in the natural environment has received greater emphasis. Over the entire duration of EI, the most common setting by far for the receipt of EI services was the home (see Figure 5), with nearly 90% of children and families receiving services at some time there. Almost a third (30%) received services at some point in a clinic or office, 22% in a family day care or nursery or preschool, 20% in a center-based EI program, and 8% in another setting.

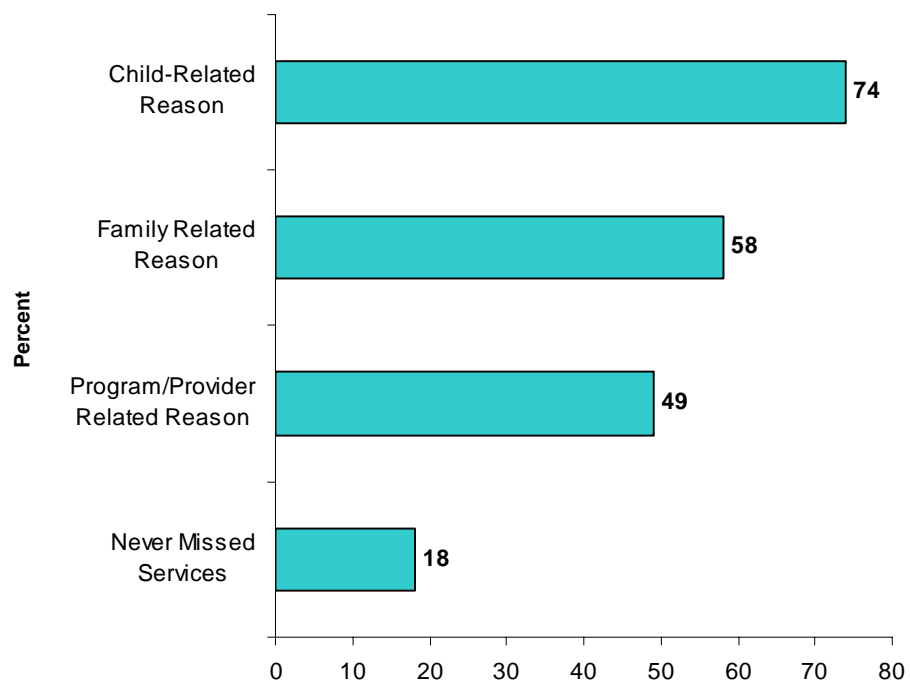
Figure 2-5. Children and Families Who Ever Received EI Services in Each Setting



Reasons Services Were Missed

As providers of any kind of service know, the amount of service scheduled to be provided and the amount received frequently differ. Missing scheduled EI services is quite likely because young children are often ill, and children in EI are in poorer health than the general population (Hebbeler, Spiker, Mallik, Scarborough, & Simeonsson, 2003). Providers were asked to indicate the reasons why the service was missed. They reported that 18% of children and families missed no services over the course of EI. Among those who did miss services, child-related reasons were most common, but family- and program-related reasons were reported relatively often as well. About three out of four families (74%) were reported to have missed services because of a child-related reason (e.g., illness), 58% for family-related reasons (e.g., scheduling conflicts), and 49% because of a program- or provider-related reason (e.g., staff not available) (see Figure 2-6).

Figure 2-6. Reasons Why Services Were Missed in EI



Conclusions

EI programs play important roles in the lives of families of infants and toddlers with special needs. According to Part C of IDEA97 families are eligible to receive a range of services to meet their identified needs, priorities, and concerns. Because EI programs are supposed to deliver comprehensive services, usually in a variety of ways, service coordination is a mandated activity, although its implementation varies across programs (Whitehead, 1996). Some EI programs coordinate the services offered in a single agency; others provide coordination for all the services family members receive, regardless of the agency involved. Therefore, service coordinators have the complex task of ensuring that families receive all services to which they are entitled. But above all, to be effective, EI services must be provided in the context of a collaborative relationship between family members and the professionals with whom they interact (Dinnebeil, Hale, & Rule, 1999).

The findings regarding the nature of EI services in Kansas over the entire course of EI of service closely mirror those found in the first 6 months of EI (Mallik & Hebbeler, 2004b):

- Speech therapy was the most frequently received service over the entire course of EI, even more than service coordination, according to the service providers most knowledgeable about the child's services.
- The service providers who were reported to work with the largest percentage of families receiving EI corresponded to the types of services that most families received (e.g., speech therapists were cited as working with the most families and, not surprisingly, speech therapy was the most frequently received service).
- A majority of families received services in the home (nearly 90%), with families typically receiving services in only one setting.
- For almost a third of children and families in EI, providers at some time consulted with a family day care provider or early childhood teacher.
- Children and families missed services for a variety of reasons, but providers described the reasons mostly as being child-related, followed by family-related reasons and program- or provider-related reasons.

These data provide a descriptive snapshot of selected characteristics of EI service delivery in Kansas throughout the duration of EI. The data are limited, however, because they are based only on children who received services to 36 months of age. Interestingly, the nature of service delivery changed very little, whether based on services received by all children and families in the first 6 months after the IFSP or on the total service history for the subgroup of children who are still receiving services at 36 months. The findings show that EI consists of a few services that many children and families receive, typically in the home, with speech therapy the most common service. The data also show that programs were the least likely to be reported as the reason children missing EI services, although a sizable percentage did miss services for program-related reasons. The association between EI services and child outcomes at 36 months is addressed in a later chapter 5.

CHAPTER 3

SERVICE PROVIDER CHARACTERISTICS IN EARLY INTERVENTION IN KANSAS

Service providers are integral to both the EI system and the children and families it serves. It is through providers' interactions with infants and toddlers with disabilities and their caregivers that the goals of the EI system are realized. Much has been written about the gap between research and practice in dealing with children with special needs (Fuchs & Fuchs, 1998; Hoshmand & Polkinghorne, 1992; Turnbull, Friesen, & Ramirez, 1998). EI providers supply the link in implementing promising practices as everyday supports for young children with disabilities and their families. This chapter examines the following topics:

- What are the demographic characteristics, training, and work settings of EI service providers in Kansas?
- What are their perceptions of their local EI systems?

Methods

Sample

The findings reported here are based on a sample of 158 individuals who provided EI services to children and families in the KIELS study sample during the first 6 months the children were in EI. At the time of a child's enrollment, the EI program provided the name and address of the service provider who was most familiar with the child and family's services. Six months after the initial IFSP, this provider was mailed a form that asked for the name and type (e.g., speech therapist) of every EI service provider who had worked with the child or family during the previous 6 months. All of the providers identified on this form were then mailed a Service Provider Survey. The data from this survey constitute the basis for the findings reported in this chapter.

Because the children had multiple providers and the data are weighted to the population of children in EI in the state, the data have been weighted separately for each provider category. Data were sufficient for four provider types for analyses. The data for each of these provider types were weighted so that the results are representative of the children and families who received services from that provider type.

Limitations

The study's findings are limited in that they are based on the responses of service providers who were identified by the child's most knowledgeable provider. The "provider lists" were not returned for all of the children and families. There could be something unique about the services and service providers of these children for whom the lists were returned that would reduce the representativeness of the sample on which the findings are based. Moreover, the knowledgeable provider may not have been aware of all service providers." Furthermore, not all of the identified providers returned surveys.

Interpreting the Numbers

The data in this chapter were weighted to represent the percent of children served in EI by a provider with a given characteristic, not the percent of providers. For example, if we assume that 92% of the children were served by physical therapists older than 30, that would not mean necessarily that 92% of the therapists were older than 30, given that their caseloads varied. To provide an illustration, consider a program that serves 100 children with 4 providers; 2 providers are women and together serve 80 of the children; the 2 male providers together serve 20 children. In this program, 80% of the children are served by women and 20% by men, but 50% of the providers are women and 50% are men. All of the data in this report refer to percentage of children.

Because the percentages are based on children and because some children have more than one provider, there are no “total” percentages that would describe the entire work force. Thus, separate percentages are presented for children served by four provider categories: service coordinators, speech therapists, special educators, and occupational therapists. (Survey data for other categories of service providers were not sufficient to include them.) The same children may be reported more than once (e.g., those with two providers are reflected in the data for both of their providers).

Because the personnel reported on in the remainder of the chapter served relatively large percentages of children in EI, the data do represent the important provider groups. The percentage of children each provider type served during the first 6 months in EI follows: speech therapist (77%), service coordinator (61%), special educator (40%), physical therapist (31%), occupational therapist (28%), and paraprofessionals (20%) (Mallik & Hebbeler, 2004b). Appendix A provides additional data tables pertinent to this chapter.

Personal Characteristics

The demographic characteristics of EI service providers can be important for several reasons: the provider’s age may indicate level of experience in the field; gender and race/ethnicity may have implications for how well providers serve children and families from diverse backgrounds and may affect providers’ compensation. The findings show that children and families were served in EI by a work force that was predominately female, white, and older than 30.

Gender. Children in EI received services almost exclusively from female providers, ranging from 96% for service coordinators to 100% for occupational therapists.

Age. Most children in EI in Kansas were served by providers older than 30 (66% for service coordinators, 79% for occupational therapists, 54% for speech therapists, and 79% for special educators).

Children who received services from speech and language specialists were the most likely to have the youngest EI providers—45% received services from someone between 21 and 30. In contrast, occupational therapy and special education providers were the oldest, with only 21% of children served by someone between the ages of 21 and 30 in these categories.

Racial and ethnic composition. Most children in Kansas (more than 90%) received EI services from providers who were white. More than 95% of children were served by service coordinators and speech therapists who were white, with more than 90% of children served by occupational therapists and special educators who were white. Previously reported data showed that 23% of the children receiving EI services in the state are nonwhite (Mallik & Hebbeler, 2002).

Languages spoken. Fluency in other languages can be an asset for EI providers, given that many children in EI do not speak English as their primary language. Likewise, fluency in sign language can be a skill useful for working with many children in EI. For most types of providers, fluency in other languages, including sign language, was limited. Children served by special educators were the most likely to have a provider who spoke a language other than English (about one in four or 23%). About one in seven (17%) of children served by service coordinators, speech therapists (18%), and occupational therapists had providers who could speak a language other than English.

Education, Training, and Work Experiences

Providers' education and work experience can affect the quality of their services and may influence how parents perceive their services.

Degree level. Children in EI in Kansas were served by well-educated providers, nearly all of whom had at least a bachelor's degree. More than 6 in 10 of the children were served by speech therapists, service coordinators, or special educators who had a master's degree. Children who were served by occupational therapists had a greater chance of having a provider with lower degree level than did other types of providers—only 26% had providers with a master's degree. A small fraction of the children served by a speech and language therapists (4%) had providers with a doctoral degree.

Professional license, credential, or certificate. The majority of children in EI in Kansas were served by providers with a specific license, credential, or certificate that qualified them to provide services in their area of expertise (see Table 3-1).

All children served by occupational therapists had providers who held licenses in occupational therapy, 98% of children served by speech and language therapists had providers who held licenses in speech and language pathology, and 89% of children served by special educators had providers who had held credentials in early childhood special education. Interestingly, 54% of children served by service coordinators had providers who held credentials in early childhood special education.

**Table 3-1. Percent of Children Served,
by Provider License, Credential, or Certificate**

	Service Coordinator	Speech and Language Therapist	Occupational Therapist	Special Educators
License/Credential/Certificate Focus				
Child development	1			4
Elementary/secondary education	35	9		51
Early childhood education	19	2		25
Early childhood special education	54	9		89
Nursing	4			2
Occupational therapy	16		100	
Audiology		3		
Physical therapy	1			
Public health				
Social work	11			<1
Special education	12	5		20
Speech/language pathology	13	98		
Other	5		2	13

Educational preparation for working with infants, toddlers, and families. Providers were asked if they had specific training to work with infants and toddlers with disabilities and delays and their families. This issue is important because training programs in specific health, education, and human services fields may or may not include specific training concerning the age group and population served in EI programs. The programs also may or may not include training in working with families.

Children served by service coordinators were likely to have providers with such training. Of those working with a service coordinator, nearly 84% of children had providers with a degree or license that involved training in working with children with disabilities/delays, ages birth to 3, and 78% had a service coordinator with training in working with families of children with disabilities. Similarly, 83% of children with occupational therapists were served by therapists whose degree/license provided them with training in working with children with disabilities, and 71% had therapists who were trained to work with the families of children with disabilities. Children served by speech therapists were highly likely (91%) to have providers who had training in working with children with disabilities, and 72% had speech therapists with some family training. Finally, children working with special educators were highly likely to have special educators with training in working with children with disabilities and with families (94% and 91%, respectively).

Years of experience. Children served by service coordinators, speech therapists, and occupational therapists were more likely to have providers with less experience in providing EI services, relative to those served by special educators. Only 21% of children served by special educators had providers with less than 2 years of experience. This proportion increased to 32% for children served by speech therapists, 35% for children served by occupational therapists, and 34% for children served by service coordinators.

Rating of preparation for working with infants and toddlers with disabilities and their families.

Providers were asked to rate how well prepared they felt they were to work with infants and toddlers with disabilities and their families, taking into account all of their education, training, and experience. The rating was based on a seven-point scale ranging from “extremely well prepared” to a rating of “not at all prepared.”

About 45% of children served by service coordinators had providers who felt they were extremely well prepared or well prepared to work with infants and toddlers with disabilities. This percentage was 32% for children served by occupational therapists, 69% for those served by speech therapists, and 29% for those served by special educators. It was encouraging that speech therapists felt the most competent in handling children with disabilities and their families, given that speech therapy is the service received by the largest percentage of children and families in EI (Mallik & Hebbeler, 2004b). This trend held for service providers’ ratings about their preparedness to work with families of children with disabilities. Once again, children served by special educators were the least likely (20%) to have providers in this category who rated themselves as well prepared or extremely well prepared to work with family members of children with disabilities. Nearly 61% of children served by speech therapists, on the other hand, had providers who reported that they were extremely well prepared to well prepared in working with families. The proportion was 32% for children served by occupational therapists and 41% for those served by service coordinators.

Employer Types

EI personnel work for a variety of agency types: public organizations, private nonprofit organizations, and other types of agencies (see Table 3-2); they are also self-employed.

Table 3-2. Percent of Children Served, by Provider Employer Type

Agency Type	Service Coordinator	Speech and Language Therapist	Occupational Therapist	Special Educator
Public agency	61	20	25	57
Private nonprofit	37	39	59	43
Private for-profit		13	3	1
Self-employed	1	14	12	
Other	<1	14		

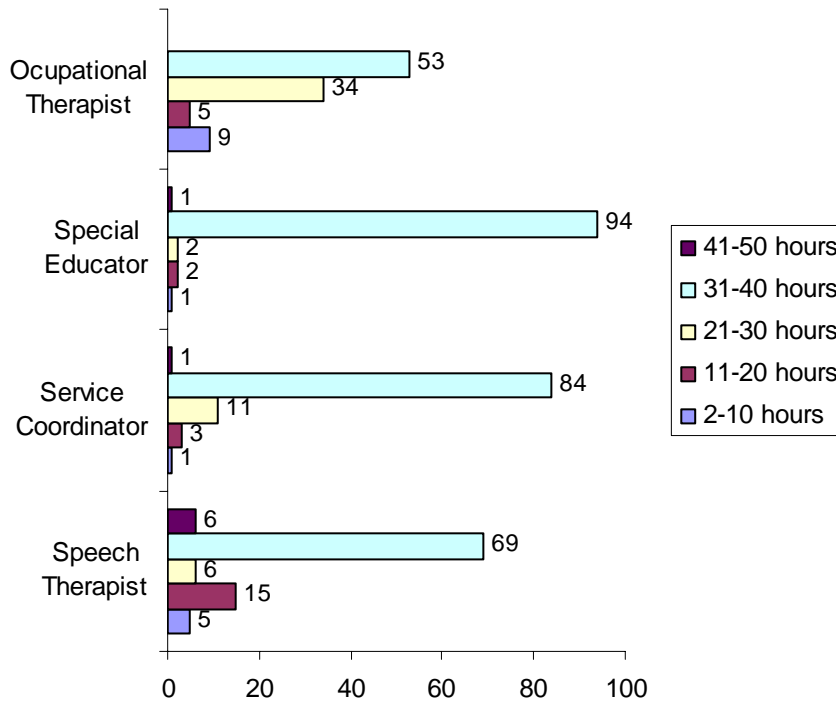
Most children who received EI services from one of these four provider types were served by professionals who worked for public agencies or private nonprofit organizations. Few were served by personnel who worked for private for-profit agencies or were self-employed. Children served by speech therapists were the most likely to be served by providers who were self-employed or worked for private for-profit agencies.

Compensation

Salary compensation is an important factor that works in tandem with other factors such as degree of motivation, professionalism, and quality of service provision to help determine the quality and stability of the EI work force.

Occupational therapists were the most likely among the four types of service providers to be employed fewer than 31 hours per week (see Figure 3-1). On the other hand, special educators were most likely to be employed full-time (94% of children served by them had providers who were employed anywhere from 31-40 hours per week).

Figure 3-1. Percent of Children Being Served by Providers, by Number of Paid Hours Worked per Week



Local EI Services: Local Interagency Coordinating Council Participation and Perceptions

The findings in this section address providers' participation in local interagency coordinating councils (LICC), and their views on issues related to system quality.

Participation in an LICC. Nationwide, LICCs have been established to facilitate the coordination of EI and other services across more than one program or agency. These LICCs can establish procedures for coordinating the delivery of services, including developing referral and eligibility determination procedures,

planning and conducting interagency trainings, and conducting community level needs assessments (see Table 3-3).

Table 3-3. Percent of Children Served, by Provider Report of Degree of Participation in an LICC and in Interagency Training

Service Delivery Characteristics	Service Coordinator	Speech and Language Therapist	Occupational Therapist	Special Educator
Presence of an LICC in the area				
Yes	95	98	87	95
Attendance at council meetings				
Never	25	46	35	21
Once or twice	24	17	26	19
Several times	4	25	8	6
Regularly	47	12	31	53
Knowledge of LICC issues and work				
Not at all informed	4	22	7	3
Somewhat informed	31	37	47	29
Fairly well informed	21	21	20	35
Very well informed	43	20	26	33
Participation in local interagency training				
Never	1	27	30	2
Once or twice	28	45	20	9
Several times	43	24	16	35
Regularly	27	4	34	54

The providers were asked several questions about the LICCs in their areas. Note that the study has no other data on whether or not a provider's area had an LICC, although the majority of provider types reported their areas did have LICCs. Practically all children served by speech therapists, service coordinators, and special educators had providers who were aware of such councils in their areas; 87% of children were served by occupational therapists who were aware of such a council in their areas. For the most part, children were served by providers who reported they were very well or fairly well informed about LICC activities and participated in trainings they provided. Speech therapist and occupational therapists were less informed than the other two provider types and were also less likely to participate in trainings.

Providers' perceptions of services for children and families in their caseload. Providers were asked for their ratings of different aspects of families' involvement and service receipt. These findings present a mixed picture of the EI system in Kansas in that the system, according to the providers, is working well for many families, but not for all. For each of the items, sizable proportions of families served by providers did not believe the system was operating as it should for all the families it was serving. The majority of families served by each of the four types of providers had providers who felt that the many or almost all of their families were actively involved in the IFSP process. Specifically, these families had providers who reported that many families were actively involved in deciding the amount, type of service, and outcomes of service

children will receive (see Table 3-4). However, only 57% of the children and families working with occupational therapists were served by those who reported that “almost all” were actively involved in deciding on the type of service they are to receive. More than 80% of children and families were served by providers who believed families welcomed IFSP meetings as a chance to talk about their services.

Table 3-4. Percent of Children Served, by Provider’s Perceptions of Families’ Participation in the IFSP Process

Service Delivery Characteristics	Service Coordinator	Speech and Language Therapist	Occupational Therapist	Special Educator
As part of the IFSP process, families are actively involved in deciding on the amount of services their children will receive				
Many (51-89%)	14	16	28	23
Almost all (90-100%)	79	73	56	69
As part of the IFSP process, families are actively involved in deciding on the type of services their children will receive				
Many	31	23	37	37
Almost all	66	71	57	56
As part of the IFSP process, families are actively involved in deciding on the outcomes of services their children will receive				
Many	19	9	6	29
Almost all	76	85	81	64
Families welcome IFSP meetings as a chance to talk about their children and their services				
Many	41	17	29	35
Almost all	47	68	56	55
Children are getting the amount of services they need				
Many	35	3	40	3
Almost all	60	97	48	97
Families are getting the amount of services they need				
Many	35	36	36	16
Almost all	54	33	46	60

Table 3-4. Percent of Children Served, by Provider's Perceptions of Families' Participation in the IFSP Process (Concluded)

Service Delivery Characteristics	Service Coordinator	Speech and Language Therapist	Occupational Therapist	Special Educator
Families do not have to fight to get what their children need				
Many	13	12	13	11
Almost all	82	82	84	80
Families are not buying EI services, in addition to those on the IFSPs				
Many	10	22	12	10
Almost all	84	75	85	89

Similarly, more than 80% of children and families were served by providers who reported that activities were coordinated across professionals for many or almost all of the families served (see Table 3-5). For example, 83% of families were working with service coordinators who believed services were coordinated for "many" or "almost all" of the families they served. Likewise, although the majority of families were served by providers who believed many or almost all of the families had their values understood and respected by professionals, it is somewhat alarming that only 45% of the families were served by occupational therapists who believed that almost all families' values were respected.

Table 3-5. Percent of Children Served, by Provider's Perceptions of Coordination and Cultural Appropriateness of Services

Service Delivery Characteristics	Service Coordinator	Speech and Language Therapist	Occupational Therapist	Special Educator
When more than one professional is serving a child or family, they coordinate their activities				
Many	20	19	37	13
Almost all	63	62	62	81
Families' cultural and family values are understood and respected by professionals who work with them				
Many	25	30	48	28
Almost all	71	58	45	67

Conclusions

Children and families were being served in EI by providers who had characteristics in common. The providers tended to be female, white, and older than 30. Most did not speak a second language or know sign language. Most were well educated (i.e., had at least an undergraduate college degree or BA), and were certified in the area of their expertise.

Although a profile can thus be drawn for EI service providers in Kansas, subtle differences existed across EI service provider types. For example, service coordinators were most likely to have training in working with children with disabilities. Special educators tended to have more years of experience. Speech therapists were especially likely to rate themselves as prepared to work with children with disabilities.

In terms of work settings, most providers were employed by public agencies or private nonprofit agencies and worked 31 or more hours per week. The providers were aware of the LICCs in their community and were involved in LICC activities. Providers had varying perceptions about family involvement in the IFSP, the way family services were coordinated, and the way families were respected. Although some reported the system was working as it should for almost all families, providers of significant percentages of families reported the system was operating as it should for many, but not all families. If the providers' perceptions are accurate, these findings suggest needs for improvement for EI in the state, especially with regard to family-centered practice. Furthermore, sizable percentages of children served by each of the four provider types had providers who did not see themselves as well prepared to work with young children with disabilities and with their families. These findings suggest that even though speech therapists, service coordinators, special educators, and occupational therapists have the necessary licenses to work with children with special needs and their families, room for improvement still exists with regard to their degree of preparedness.

CHAPTER 4

LENGTH OF STAY IN EARLY INTERVENTION

EI programs can continue to provide services to children and families until the child reaches 36 months of age, although little information is available about how many children remain in the programs until age 3 and why those who leave earlier do so. The number of months over which children and families receive EI is an important consideration because of the outcomes likely to be achieved and also has important implications for service issues such as staffing and expenditures. This chapter focuses on the time children in Kansas spend in EI. It also describes differences between children who stayed until the end of their eligibility (i.e., 36 months) and those that did not. The following questions are addressed:

- How long do children and families stay in EI?
- Who are the children that leave EI before 36 months of age and why do they do so? How do they differ from those children and families that stay?

How Long Do Children and Families Stay in EI in Kansas?

Somewhat more than half the EI entrants continued to receive EI services from the time they entered until the end of their age eligibility for EI (i.e., 36 months of age). The information on EI status comes from two sources: the family interview conducted when the child was 36 to 40 months of age and the Service Record (SR) form, which one of the child's providers completed and returned to the study team. Figure 4-1 highlights the status of EI recipients at 36 months. Most (54%) were still in EI at 36 months, 20% were no longer receiving services, the status of 16% was unknown, 8% of children and families had moved out of Kansas, and 2% of children had died. The child's status remained unknown if the study team was unable to locate the family for an interview when the child turned 36 months of age and if the service provider did not submit an SR form at that time and had not previously submitted an SR form indicating the child and family were no longer receiving service.

Children enter EI at all points between birth and 36 months (Mallik & Hebbeler, 2002) and thus even if all children stayed until they were no longer age-eligible, children would receive services for different periods. Most children (58%) received EI services for 12 months or less (see Figure 4-2). Nearly 80% of children received EI services for 18 months or less. Only 14% received services for 25 months or more. Knowing the duration of time over which children receive services is important for understanding the potential impact that services can have. Even though EI is a program for birth to 3-year-olds, very few children received services for 3 years. Indeed, most received services only for a year or less.

Another important issue is the number of children who received services for the maximum duration they could have. We defined maximum duration as the extent of time between when the child first began to receive services and when the child turned 36 months of age. We then calculated a percentage using the months over which the child actually received service; that is:

$$\text{Percent of Maximum Duration} = \frac{\text{Months Received Services in EI}}{\text{Time between Entry to EI and 36-month Birthday}}$$

For example, if a child began service at 24 months of age and continued to receive service until 36 months, the child's percent of maximum duration would be $12/12$ or 100%. That is, the child received EI services over the entire duration of time for which he/she was eligible, given the age at which the child entered EI. For this analysis, any child who received services past his or her 36-month birthday was still considered as having exited services at 36 months.

Figure 4-1. Status of Children in EI at 36 Months

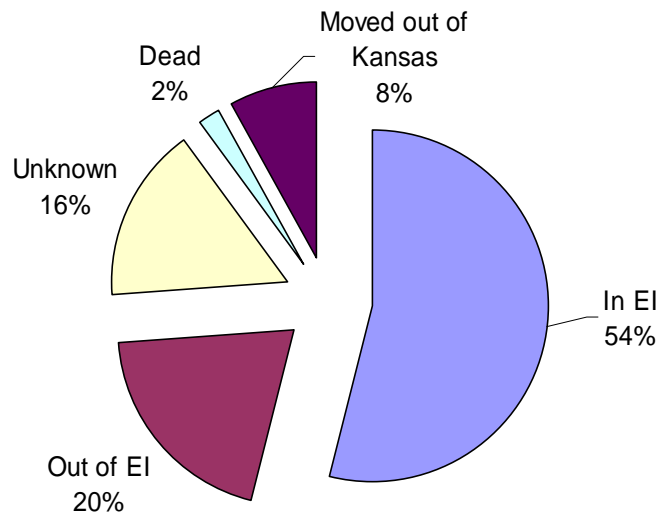
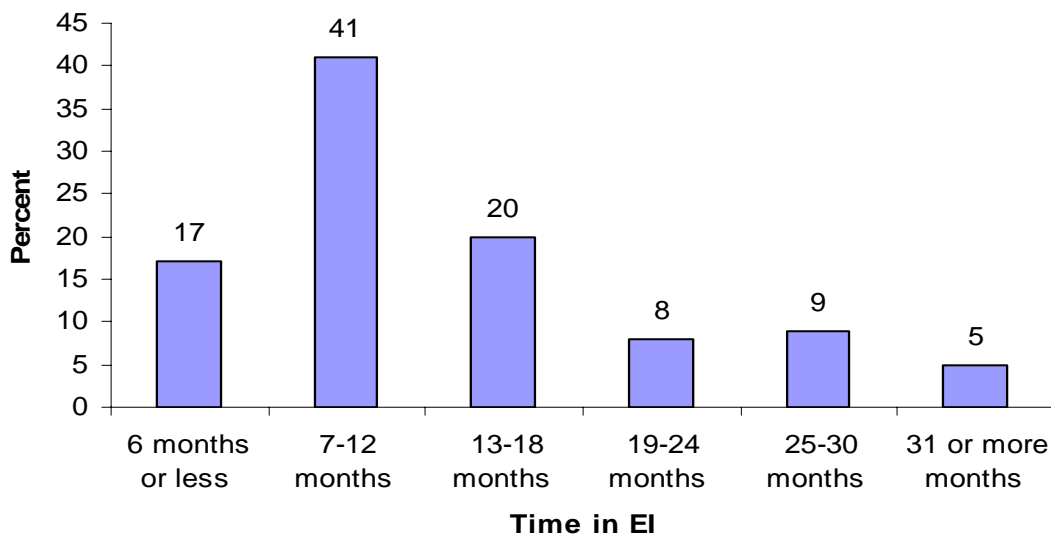
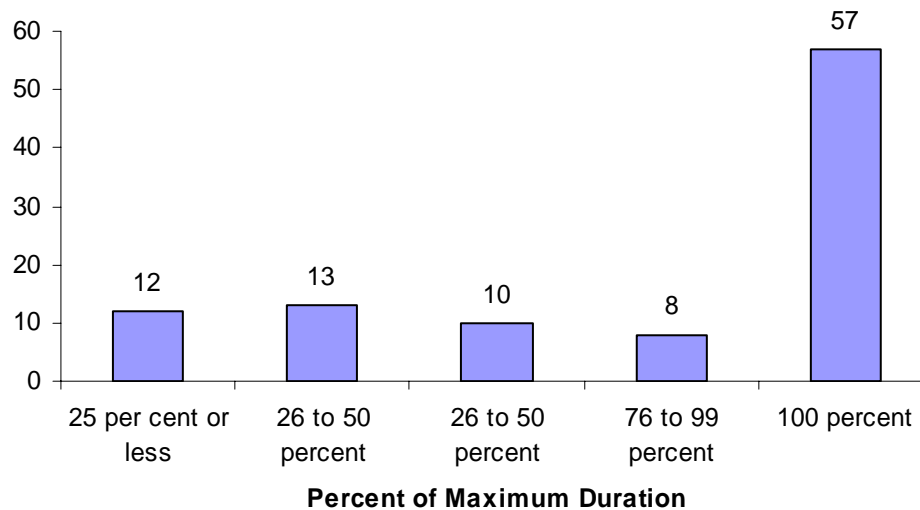


Figure 4-2. Months Spent by Children in EI in Kansas



Most, but not all, children in EI received the maximum number of months of service from the time when they began services. As shown in Figure 4-3, 57% of children in EI received EI services for the maximum number of months, based on their age at entry into the system. On the other hand, a quarter of children stayed for 50% or less of the time between entry and 36 months.

Figure 4-3. Percent of Maximum Duration in EI



Characteristics of Families and of their Children who Leave EI before 36 Months of Age

A child or family could stop receiving EI services before 36 months of age for several reasons, and one of them is good—the child could have made substantial developmental progress and was thus no longer be eligible for services. On the other hand, families could have decided they no longer were interested in services and ended them. On the other hand, families might have been pleased with the services but faced too many life challenges, were not available for home visits, or were unable to bring their child for appointments consistently. Some of these families “disappeared” from the programs without ever formally withdrawing. When a family was known to have exited EI, service providers were asked to indicate the reason for doing so. Of those children and families that left EI before the child was 36 months old, the following reasons were cited to explain their departure: 13% moved, 8% discontinued services, 2% had a custody or household change, and 73% were no longer eligible for services; 4% were unable to be contacted.

To provide additional information on the families who left EI before the child’s 36-month birthday, the characteristics of children and families who were known to have still been enrolled in EI at 36 months were contrasted with characteristics of those who left early or whose exit time was unknown (see Table 4-1). The analysis excluded children who died and families who moved out of the state.

**Table 4-1. Characteristics of Families and their Children,
Based on the Child's EI Enrollment Status at 36 Months**

End Status	Enrollment Status (%)	
	In	Out/Unknown
Total	100	100
Child's gender		
Male	68	60
Female	32	40
Child's race/ethnicity		
White	82	77
Minority	18	23
Child's age at entry into EI/Initial IFSP		
Up to 11 months	22	57
12 months to 24 months	29	28
Older than 24 months	49	15
Child's eligibility category		
Developmental delay	89	77
Established risk of developmental delay	11	23
Primary caregiver's educational attainment		
Less than high school degree	10	10
GED or high school degree	32	30
Some college	29	39
Bachelor's degree or higher	29	22
Household income		
Less than \$15,000	15	25
\$15,001-\$25,000	21	8
\$25,001-\$50,000	33	31
\$50,001-\$75,000	18	21
More than \$75,000	13	15

The most striking difference between the two groups is the child's age at entry to EI. Children who began to receive EI at older ages were more likely to still be enrolled at 36 months of age; stated another way, the children most likely to leave EI (or to have unknown status) before 36 months were those who began services as infants or young toddlers. A larger proportion of children that were out of EI or unknown at 36 months, entered EI when they were younger than 12 months (57%), versus those that were in EI at 36

months (22%) ($p < .001$). The group of children who begin EI services younger than 12 months are eligible for services for a variety of conditions, some of which are life-long disabilities (Hebbeler et al., 2001). These data suggest that other children who may have been receiving EI for factors related to a difficult birth history such as low birth weight no longer needed services by 36 months; alternately, the families of children who started services very young were no longer interested in receiving the services. The differences in the age groups also are reflected in reasons for eligibility, with a larger proportion of children still receiving services at 36 months with developmental delays (89%) relative to those who were no longer receiving services or whose status was unknown (77%). Children with developmental delays begin services at much later ages. These differences however, were not of statistical significance.

Conclusions

Findings that indicate no standard period for children staying in EI further highlight that no child in EI is “typical” (Hebbeler et al., 2003). The data presented here demonstrate that many EI participants do not continue to receive EI services until their 3- month birthday. A majority receive services for 12 months or less, and nearly 80% receive services for fewer than 18 months. Only 57% receive services for the entire span of time between when they begin services and their 36-month birthday. Examination of the characteristics of children and families who cease services before the child’s 36-month birthday showed that the children most likely to receive services through 36 months began services later and, conversely, those most likely not to be receiving services at 36 months of age began services at the youngest ages. The reasons for these differences may have occurred have been derived in this chapter from data gleaned from children’s service records. Our analyses suggest that more work needs to be done to address why families are leaving services before their children are 36 months of age and that program changes need to be made if the reasons for leaving services are family issues rather than a child’s attainment of goals.

CHAPTER 5

CHILD OUTCOMES AT 36 MONTHS IN EI

A critically important issue is the kind of developmental competencies that young children are achieving over their time in EI programs. Much work remains to be done in conceptualizing and measuring outcomes for young children with disabilities (Early Childhood Outcomes Center, 2004). An overall goal of EI related to child outcomes is to maximize the developmental potential of each child. This goal, however, cannot be measured because we cannot know the potential of any child. It is possible, however, to describe the developmental and functional status of children when they enter EI and to look at the growth they have shown by the time they exit the program. Given how little is known about the characteristics of young children receiving EI, good descriptive information about what the population of young children looks like with regard to changes in functioning and development provides an important first step for understanding how to improve programs to produce even better outcomes.

This chapter addresses the following questions:

- What are the outcomes at 36 months for children who have received EI services?
- How do child outcomes relate to variations in child and family characteristics and services received?

What are the Outcomes at 36 Months for Children who Have Received EI Services?

Functioning. Parents were asked to report on whether their child may or does have a problem in vision and hearing (see Table 5-1). Parents who answered “yes” were then asked a series of follow-up questions, including whether the problem had been diagnosed by a professional. Only 10% of the children receiving EI services were reported by parents to have a vision problem when they began EI. This percentage remained approximately the same when the children were 36 months of age. Parents reported that 21% of the children receiving EI services had a hearing problem at entry. By 36 months, parents reported that only 10% of the children had hearing problems. Some hearing problems such as those related to recurring ear infections may be transitory. In addition, the children may have received necessary treatment for their hearing problems after entering EI.

Table5-1. Vision, Hearing, and Use of Arms and Hands, and Legs and Feet, in Children Entering EI and at 36 Months

Child functioning	Entry	36 Months
How is eyesight?		
Sees normally	90	91
Vision problem	10	9
Hearing		
Hears normally	79	90
Hearing problem	21	10
How well does child use arms and hands?		
Uses both normally	80	88
A little trouble	17	10
A lot of trouble/Not using one or both	3	2
How well does child use legs and feet?		
Uses both normally	80	86
A little trouble	17	12
A lot of trouble /Not using one or both	3	3

Parents were asked to report on their children's use of arms and hands, and legs and feet, compared to other children of the same age. About 20% of the parents described their children as having either a little trouble or a lot of trouble using their legs and feet and arms and hands at entry. By 36 months, fewer parents reported difficulties: 12% were reported to have a little or a lot of trouble with arms and hands, and 15% were reported to have a little or a lot of trouble with legs and feet.

Parents were asked two questions about the child's communication abilities: How well does the child make his or her needs known to others compared to children of the same age? and How easy it is to understand the child when the child talks to people he or she does not know? This item was particularly relevant for those children that were 12 months or older at entry into EI (see Table 5-2). Parents reported that (72%) of the children had a little to a lot of trouble making their needs known at entry. Because many of the children (33%) were under 12 months of age when they began to receive EI services, this question did not apply to them. By 36 months, 67% were reported to have a little to a lot of trouble communicating—a slight reduction. Parents reported 39% of children as being somewhat hard to very hard to understand at entry. By 36 months, this percentage had increased to 48%. These data suggest that a population of children for whom speech and communication was a need area emerged over their time in EI. This is not surprising, given the sizable proportion of infants with disabilities who were not yet old enough to be expected to be able to communicate with words at entry to EI. As these children grew older, their problems in these areas emerged.

**Table 5-2. Communication Abilities of Children Entering EI in Kansas
(for Those 12 Months or Older at EI Entry)**

Communication characteristics	Entry	36 Months
How well does child make needs known?		
Communicates well	24	33
A little trouble	52	47
A lot of trouble	20	20
Does not communicate	4	0
Others' understanding of child's speech		
Very easy	3	7
Fairly easy	6	29
Somewhat hard	28	36
Very hard	11	12
No words	53	16

Health Status. A large proportion of parents rated the health status of their children in EI as very good or excellent (65%) when the family began EI. This percentage increased to 74% at 36 months. Only 12% of children were reported to have been in fair or poor health at entry, and this percentage was only 7% at 36 months.

In summary, most children showed good functioning in most of the areas examined and were healthy at the time they began EI. These are overall population data and reflect each area looked at separately. Within each area, functioning was a minor or significant problem for some children. Communication distinguished itself from the other areas in that far more children were reported to have communication problems. The status of the population in each of the areas looked very similar at 36 months, with even more children showing difficulties in communication.

Development and Behavioral Characteristics

Developmental Competencies. To examine developmental progress, the research team identified key competencies for five developmental areas: social, cognitive, motor, language, and self-help. For each competency, parents were asked to report whether the child "doesn't do it at all yet," "does it but not well," or "does it well." Individual competencies were selected because the literature had shown them to be universal in expression, and pilot testing confirmed that they could be reported on by parents.

Parents rated their children's attainment of key developmental competencies at the time they entered EI and at 36 months. Data are reported for three ages groups: children who were younger than 12 months at initial IFSP, those aged 12 to 24 months, and those older than 24 months. As expected, the relationship between age and the percentage of children who can perform a given item was strong. Table 5-3 presents the percentage of parents of children in each age group who reported the child could do the item well at entry to EI and at 36 months. Also provided for each item is the age when approximately 90% of the general population can perform this task. The reader is reminded that these three groups of children differ in other important ways in addition to age. The children who enter EI at the youngest ages were more likely to be eligible for EI because of an established risk for developmental delay, were more likely to have had a low birth weight, and were more medically involved (Mallik & Hebbeler, 2002).

With regard to mobility at entry into EI, most but not all children in EI who were 24 months of age or younger could crawl or sit alone. Even though 90% of the general population is able to crawl or sit alone at 11 months or earlier, in EI 4% of children 12 to 24 months were not yet crawling, and 3% of children in this age group could not sit unassisted. Walking without holding on to anything, the ultimate mobility attainment of toddlerhood, was done well by 79% of those in the 12- to 24-month age group and by 98% of those in the group older than 24 months at entry to EI. By the time these children were 36 months, all the children who entered EI at 12 months or older could crawl and sit alone. Of those 12- to 24-months old at entry, 4% could not walk without holding on to something at 36 months.

Table 5-3. Percentage of Children Attaining Selected Developmental Competencies at EI Entry and at 36 Months of Age

Developmental milestones	Age at IFSP					
	<12		12-24		>24	
	E	36	E	36	E	36
Mobility						
Crawls, scoots, creeps (11)	39	95	96	100	100	100
Sits alone (11)	39	95	97	100	100	100
Walks without holding on to anything (17)	<1	80	79	96	98	100
Hand Use						
Grasps and releases (10)	66	91	98	97	100	100
Picks up small things (12)	28	79	92	94	98	92
Communication						
Brightens, smiles on hearing own name (7)	79	94	99	92	99	100
Gestures to communicate (12)	32	90	94	94	99	99
Says "mama" or "dada" (12)	13	86	64	88	86	97
Responds to simple verbal requests (13)	9	80	53	87	92	88
Says at least 20 words (17)	0	61	8	64	42	80
Repeats or imitates a word someone says (18)	5	62	22	70	38	70
Says at least 2 or 3 words together in a sentence (25)	0	59	8	66	30	65
Independence						
Eats bite-size food with fingers (11)	21	90	98	99	100	100
Holds cup to drink (18)	12	85	92	87	96	100
Takes off socks without help (23)	25	44	71	84	82	96
Object Play						
Explores/manipulates objects (11)	52	88	100	93	98	95
Puts things into and out of things (12)	24	87	88	92	96	95
Social Play						
Responds to the peek-a-boo game (8)	71	87	100	88	98	96
Greets people with a wave, smile, or "hi" (24)	58	86	82	88	96	94

Note: E = at entry to EI; 36 = at 36 months. The number in () after the item is the age at which the skill is mastered by 90% of the general population.

The two milestones related to hand use show the same pattern: more children attain success at older ages, but some children also lag behind. Ninety-two percent of children 12-24 months and 98% of the older group were able to pick up small things when they began EI. Because nearly all children in the general population have attained this skill by 12 months, these data reflect a small percentage of children in the EI population who had fine motor difficulties.

The milestone data on communication reinforce earlier findings about the predominance of communication problems within the population of children in EI. Many children were able to respond to their names and communicate with gestures, but fewer, even among the older groups at entry to EI, were able to use words. Whereas children in the general population say “mama” or “dada” by 12 months of age, only 64% of those 12 to 24 months of age when entering EI had attained this skill. Even among those over 24 months, only 86% said “mama” or “dada.” The other communication milestones present a similar picture. Most children in the general population say at least 20 words by 17 months. Among those entering EI who were older than 24 months, only 42% were reported to say at least 20 words. Although this proportion increased by the time these children were 36 months to about 80%, 20% of children who entered EI at older than age 2 still could not say at least 20 words at age 3. Two-thirds or less of each age group at entry could use 2 to 3 words sentences at 36 months of age, a skill typically mastered by 25 months. These findings strongly demonstrate the need to address communication skills in this population.

On entry to EI, the older children were relatively successful with regard to independence. Most of the 12- to 24-month-olds (98%) could eat bite size food with their fingers, as could all of those older than 24 months. Most of the children in each of these groups could also hold a cup to drink (92% and 96%, respectively). Taking off socks was more difficult, but this is a skill not usually mastered until 23 months of age. Eighty-two percent of the children older than 24 months could take their socks off without help when they began EI services. By 36 months, many children had mastered holding a cup, but some, especially those who began EI as infants, still could not take off their socks.

The children entering EI were also relatively successful in the areas of manipulating objects and social play, although, as in all areas, some children were experiencing difficulty. For example, putting things in and out of things is normally mastered by 12 months of age in the general population. Among those 12 to 24 months old at entry to EI, 88% could do this well. Among those older than 24 months, only 4% of the oldest children were not able to put things in and out of things. By 36 months, many children in all three age groups at entry were able to do this. Responding to people with a wave or a smile was also mastered by most EI participants by 36 months.

Overall, the results for attaining developmental milestones among children entering and leaving EI indicate that small percentages of children had difficulty in each of the developmental areas (not necessarily the same children) as evidenced by delayed mastery of age-appropriate skills. The notable exception was in the area of communication, where the percentages of children with delayed attainment were far greater than in the other domains. As seen in previously presented data, this further reinforces the finding that infants and toddlers in the state experience a variety of different developmental problems, but many of them have communication problems.

Engagement Behavior. Parents were asked a series of questions about different aspects of their child’s behavior, including how the child interacted with the environment and with other children and adults. These items differ from the developmental competencies in that many of these behaviors or traits do not have a predictable developmental trajectory (notwithstanding that almost all behavior will change as children grow older). Items addressed a variety of behavioral attributes, including involvement, persistence, social engagement, activity level, distractibility, threshold to respond, and attention. For many of these items, parents were read a description and asked how much it was like their child. Parents responded by indicating this was not like their child, a little like their child, or very much like their child. Parents’ responses to these questions are shown in Tables 5-4 and 5-5. As indicated in the table, several of the items were not asked of parents of children younger than 12 months of age. The wording on some of the items was also modified slightly for the younger children.

**Table 5-4. Percentage of Children Showing Behaviors and Traits
at EI Entry and at 36 Months of Age**

Behavior	Age at IFSP					
	<12		12-24		>24	
	E	36	E	36	E	36
Child is quiet and passive.						
Very much like child	8	14	12	11	7	10
A little like child	21	21	29	25	24	37
Not like child	71	65	58	64	70	53
Child is jumpy and easily startled.						
Very much like child	26	18	7	13	17	9
A little like child	42	39	33	25	23	29
Not like child	31	42	61	61	61	61
Child pays attention and stays focused.						
Very much like child	57	54	35	57	35	32
A little like child	32	27	43	31	39	38
Not like child	10	19	22	12	26	31
Child does things on his/her own, even if hard.						
Very much like child	NA	51	69	70	65	65
A little like child	NA	37	23	22	29	24
Not like child	NA	12	8	8	6	11
Child tries to finish things.						
Very much like child	NA	20	18	39	23	19
A little like child	NA	44	41	46	36	46
Not like child	NA	36	41	15	41	35
Child is very active and excitable.						
Very much like child	1	27	37	29	48	39
A little like child	1	42	33	35	23	33
Not like child	5	31	30	36	29	27
Child is easily involved in everyday things.						
Very much like child	63	52	57	60	44	62
A little like child	20	33	25	32	52	31
Not like child	17	15	19	8	4	7
Child is distracted by sights and sounds.						
Very much like child	NA	13	15	22	13	29
A little like child	NA	33	28	32	51	34
Not like child	NA	55	57	46	36	37

**Table 5-4. Percentage of Children Showing Behaviors and Traits
at EI Entry and at 36 Months of Age (Concluded)**

Behavior	Age at IFSP					
	<12		12-24		>24	
	E	36	E	36	E	36
Child shows interest in nearby adults.						
Very much like child	66	47	36	46	45	47
A little like child	28	38	30	42	37	30
Not like child	7	15	34	11	18	23
Child plays with other children.						
No trouble	NA	67	61	50	54	39
Some trouble	NA	25	30	40	44	58
A lot of trouble	NA	7	6	10	1	3
Not around children	NA	1	3	0	0	0

Note: E = at entry to EI; 36 = at 36 months. NA = The item was not asked if child was younger than 12 months of age.

Table 5-5. Percentage of Children Showing Engagement Characteristics at EI Entry and at 36 Months of Age

Engagement characteristic	Age at IFSP					
	<12		12-24		>24	
	E	36	E	36	E	36
How aggressive is child with other children?						
Not at all	NA	46	42	32	27	30
Sometimes	NA	50	55	55	61	60
Often	NA	4	3	13	11	10
How easy is the child to soothe/manage?						
Easy	47	54	47	33	41	41
Sometimes hard	47	39	30	55	50	49
Often hard	6	7	23	11	9	10
How often does child have temper tantrums?						
Rarely or never	NA	28	24	16	13	22
Sometimes	NA	52	50	44	67	54
Often	NA	19	26	40	20	24
How often does child have trouble sleeping?						
Rarely or never	52	54	62	45	56	63
Sometimes	32	34	19	21	29	18
Often	16	12	20	33	15	19
How easy is it to take child to a store or an appointment?						
Easier than with other children	27	15	22	16	22	24
Just as easy	38	62	50	39	55	47
A little harder	23	17	21	30	17	24
Much harder	12	6	7	15	6	4
How easy is it to get a babysitter?						
Very easy	47	38	62	59	66	64
Fairly easy	28	46	24	30	25	17
Somewhat hard/Very Hard	25	16	14	11	9	19

Note: E = at entry to EI; 36 = at 36 months. NA = The item was not asked if child was younger than 12 months of age.

Most children (63%) in EI at entry were described as not quiet or passive. Children who were younger at entry were more likely to be rated as jumpy and easily startled at entry and at 36 months relative to children who entered EI at older ages. Many parents reported that paying attention and staying focused was very much like their child, or a little like their child. However, at 36 months 31% of parents of children who were older than 24 months said this was not at all like their child, as did 19% of the parents of children who entered at less than 12 months. A relatively large percentage of children were reported as not trying to finish things at 36 months of age—36% of children who began EI younger than 12 months of age and 35% of those who began when older than 24 months. Many parents saw their child as excitable and active at 36 months; 39% of those with children over 2 at entry said this was very much like their child. Similarly, 29%

of parents of children over 24 months at entry said being distracted by sights and sounds was very much like their child, and another 34% said this was a little like their child. Many children, especially those who began EI at older ages, were characterized as having some trouble or a lot of trouble playing with other children at 36 months and in being aggressive with other children. Many children were also described as sometimes or often hard to manage at 36 months regardless of the age at which they began EI. Many were also reported to have temper tantrums at 36 months. Sleep problems were less common among those who entered EI younger than 12 or older than 24 months, compared with the middle group; a third of children in EI who were between 12 and 24 months at entry were described as often having sleep problems. In addition, for this same group of entrants, parents were more likely to report the child was a little or much harder to take with them to the store at 36 months of age.

Changes from Entry to 36 Months in Child Outcomes: Functioning

The analyses presented thus far have looked at the status of the population of children who received EI. The status was described at two time points: when they entered EI and at 36 months of age. Another way to look at changes in outcomes is to track changes in individual children and ask whether that child's status changed from entry to 36 months. The findings in this section address change in individual children.

Hearing. Figure 5-1 depicts the change in hearing status for the children in EI from entry to 36 months. Eighty-five per cent of children were reported by their parents to hear normally at entry, and to hear normally at 36 months. Eight percent were reported to have hearing problems at entry but not at 36 months. A small proportion had no hearing problems at entry but did have a diagnosed problem by 36 months of age (2%), and 5% had a hearing problem at entry as well as at 36 months.

Vision. Eighty-nine per cent of children were reported to have normal vision when they began EI, and at 36 months (see Figure 5-2). Two percent had a vision problem at entry but not at 36 months. A small proportion were diagnosed with a vision problem after entry to EI (6%), and an even smaller proportion (2%) had a vision problem at entry as well as at 36 months.

Figure 5-1. Change in Hearing Status: EI Entry to 36 Months

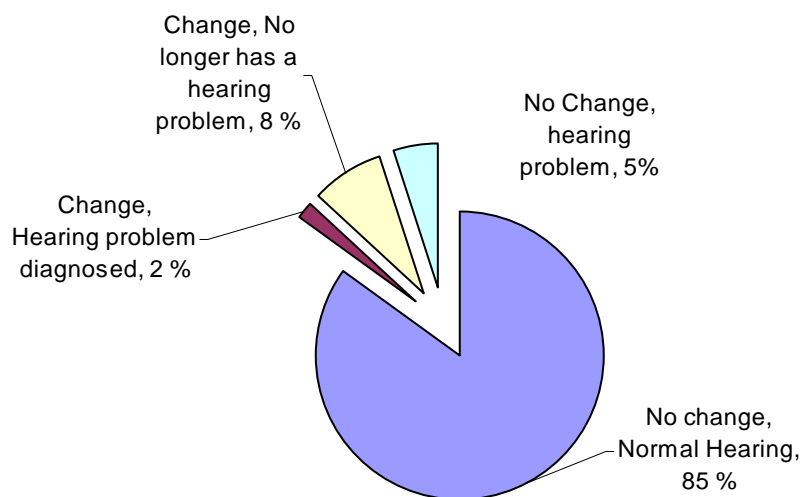
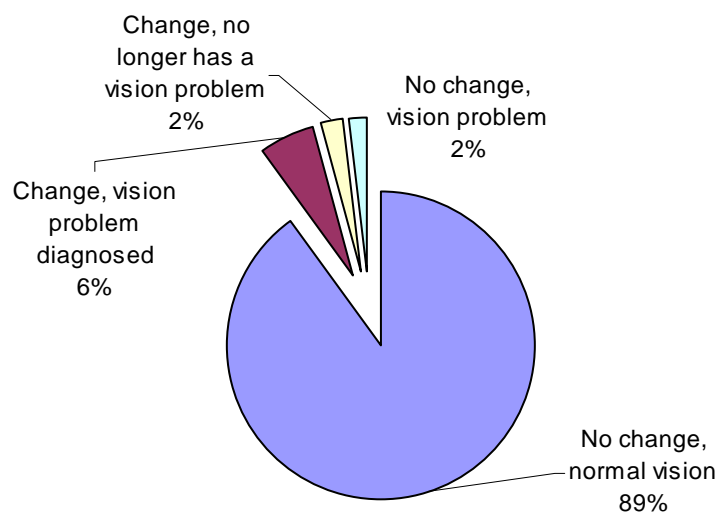
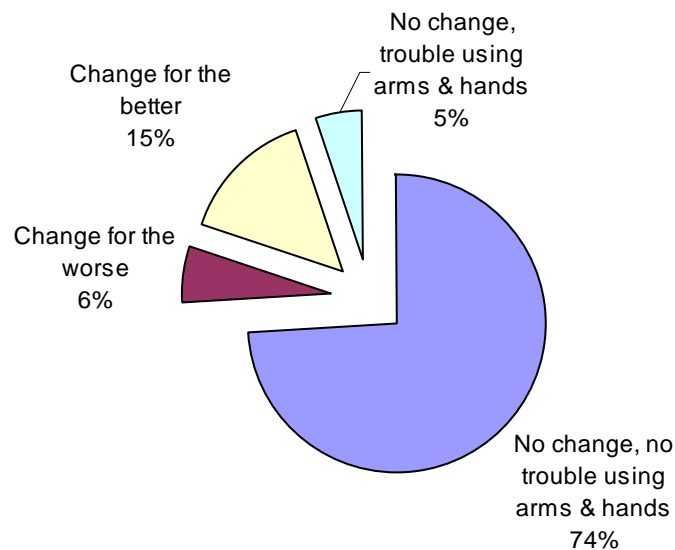


Figure 5-2. Change in Vision Status: EI Entry to 36 Months



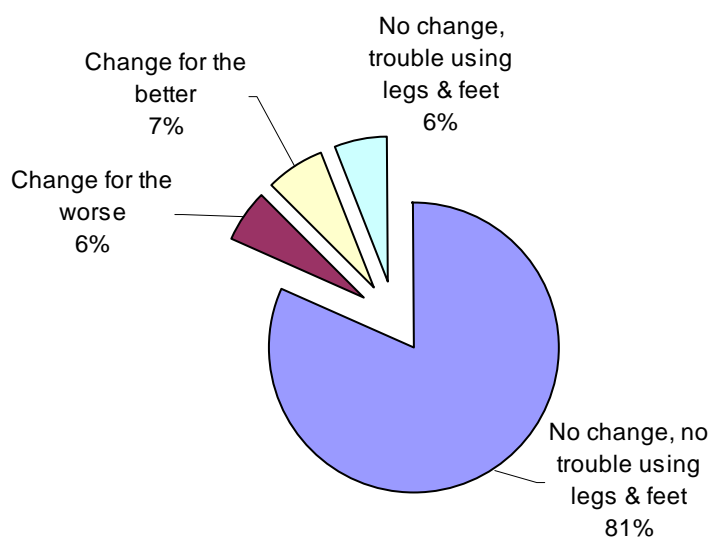
Use of Arms and Hands. Seventy-four per cent of children were reported to use their arms and hands normally at entry, and at 36 months (see Figure 5-3). For 15%, parents reported a higher level of use at 36 months than what they had reported at entry to EI (e.g., reporting “a lot of trouble” at entry and “a little trouble” at 36 months). These are children whose functioning relative to typically developing children would be considered to have improved over their time in EI. A small proportion were reported to have problems or more serious problems in arms and hand use at 36 months (6%), and 5% had the same level of problems at entry as well as at 36 months.

Figure 5-3. Use of Arms and Hands: EI Entry to 36 Months



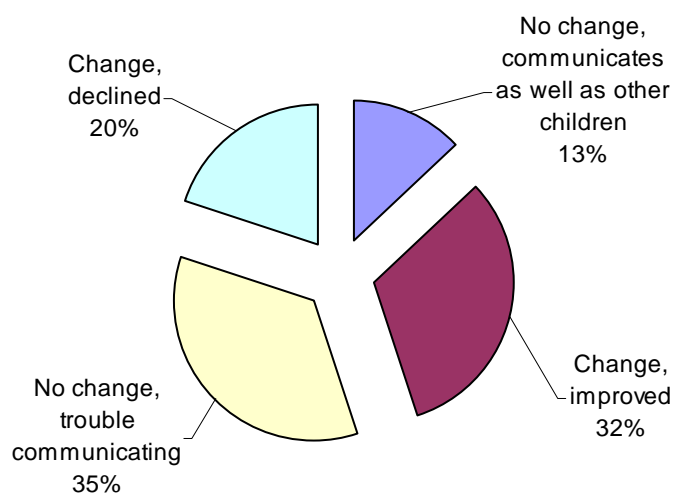
Use of Legs and Feet. Eighty-one per cent of children were normally using legs and feet at entry and at 36 months (see Figure 5-4). Seven percent showed improved use of legs and feet at 36 months compared to their status at entry. A small proportion were rated as having more difficulty compared to normal at 36 months than at entry (6%), and another 6% had a the same level of problems at entry as well as at 36 months with legs and feet use.

Figure 5-4. Use of Legs and Feet: EI Entry to 36 Months



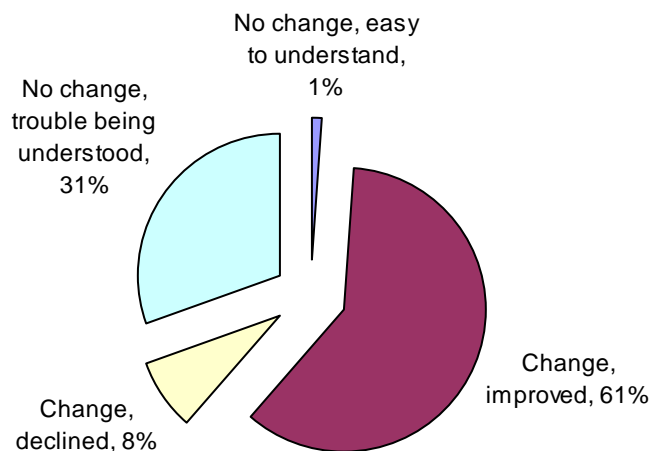
Communication: Making Needs Known. As noted above, many children in EI had problems related to communication. The data on changes in communication are reported only for those older than 12 months of age because the items were not asked if the child was younger than 12 months of age at entry. Only 13% were reported to communicate their needs as well as other children at entry and at age 3 (see Figure 5-5). Thirty-two percent were given a higher rating at 36 months than at entry, meaning they improved their communication skills relative to typically developing children. One in five received a lower rating at 36 months. More than a third had the same level of difficulty communicating their needs at entry and at 36 months. For children younger than 12 months at entry, 55% were reported to communicate their needs just as well as other children at 36 months, 28% had a little trouble, and 17% had lots of trouble.

**Figure 5-5. Change in How Well Child Makes Needs Known:
EI Entry to 36 Months (for Children Older than 12 Months)**



Communication: Being Understood By Others. Of those children older than 12 months at entry into EI, less than 1% were reported to be easy to understand at entry as well as at 36 months, 61% were given higher ratings in this arena by age 3, and 8% were reported to be less understandable at 36 months (see Figure 5-6). Almost a third (31%) were reported to have the same level of difficulty being understood at entry as well as at 36 months. Of those children younger than 12 months at entry, 53% were very easy to fairly easy to understand by the time they were 3, 15% were somewhat hard to understand, and 7% were very hard to understand.

**Figure 5-6. Change in How Well Child is Understood:
EI Entry to 36 Months (for Children Older than 12 Months)**



Variations in Child Outcomes

Little is known about which children make the best progress in EI. This is still the case despite a long-standing recommendation that the question that needs to be addressed regarding the effectiveness of EI is not "is EI effective," but "for which children is intervention effective under what circumstances?" (Guralnick, 1997). To begin to address this second question, the findings in this section address how outcomes vary as a function of child and family characteristics and as a function of services received.

The following child outcomes at 36 months were examined:

- General health
- Hearing status
- Vision status
- Use of arms and hands
- Use of legs and feet
- Making needs known
- Understandability of speech
- How well needs are made known.

Outcomes and Child and Family Characteristics

The analyses examined the following child and family characteristics:

- Reason for eligibility (developmental delay, diagnosed condition, at risk)
- Gender (male, female)
- Race/ethnicity (white, other)
- Age at IFSP (birth-younger than 12 months, 12 months-younger than 24 months, 24 months-younger than 36 months)
- Family characteristics:
 - Maternal education (less than high school, high school or more)
 - Household income (less than \$25,000 per year, more than \$25,000 year)
 - Single-parent household (child in household with one adult; child in household with two or more adults)

Outcomes for children and families with different characteristics differed in certain respects. Children who were not white were more likely to have been reported to have had little to a lot of trouble (23%) using their arms and hands at 36 months, compared with those who were white (9%) ($p<.05$). Children in households with annual incomes of \$25,000 or less were more likely to have trouble communicating their needs (72%), compared with those in households with incomes exceeding \$25,000 (55%) ($p<.05$). Children who were older at entry (older than 24 months) were more likely to have a little or a lot of trouble making needs known at 36 months (72%), compared with children who began EI at younger than 12 months (47%) ($p<.02$).

Outcomes and Services Received

One of the analyses of the 36-month child outcome data looked at how Service Record (SR) data gleaned from children in EI in Kansas were associated with child outcome data collected from transition family interviews. We report in this section on 228 children and families that had data collected from at least one SR and for whom a transition family interview was conducted. This was not a regression but a bivariate analysis

Characteristics of services that were examined included:

- Whether or not the child had received each of the 23 services over the entire time in EI (see Chapter 2 for the list of services)
- Whether or not the child had received services from each of 23 service provider types over the entire time in EI (see Chapter 2 for the list of providers).
- Whether or not the child had received in each of the five service settings over the entire time in EI (home, center, clinic, preschool, other)

Child outcomes that were examined included:

- General health
- Hearing status
- Vision status
- Use of arms and hands
- Use of legs and feet
- Making needs known
- Understandability of speech
- How well needs are made known.

No significant relationships were found between any of the service characteristics and the outcomes demonstrated by children at 36 months of age.

Conclusions

This chapter has highlighted the following findings on child outcomes at 36 months:

- Few children have problems in the areas of vision, hearing, and motor skills, and that proportion stays relatively constant over time—although individual children improve or decline. Far more children have problems in communication. Many children show improvement over time; however, communication continues to be a challenge for many EI graduates.
- Most children make progress in different developmental arenas. However communication is still an area in which many children in EI are challenged.
- Some children who had participated in EI displayed challenging behaviors at 36 months. The proportion varied with the type of behavior being examined, with temper tantrums and aggressive behavior being relatively common. On the other hand, many children were reported to be behaving in way that would be considered typical.

In conclusion, the EI system in Kansas served children with a variety of developmental needs who entered the program at every age point between birth and 36 months of age. This chapter has provided descriptive information about the functional, developmental, and behavioral characteristics of the children who were being served by EI and what they looked like at the end of EI. Although developmental progress was made by all these children, children were challenged in some distinct areas—communication was one such area. It is encouraging, given the prevalence of communication problems, that some children were reported by their parents to be communicating better relatively to typically developing peers after receiving EI services.

CHAPTER 6

FAMILY OUTCOMES AT THE END OF EARLY INTERVENTION IN KANSAS

Families play an integral role in the EI system in the United States. Part C of IDEA97 replaced the Individualized Education Program (IEP) for children ages 3-21 with the Individualized Family Service Plan (IFSP) for infants and toddlers with disabilities, thereby elevating the family component of EI to a new level. To develop the IFSP, EI programs must incorporate a family-directed assessment of family resources, priorities, and concerns. Furthermore, if the family so desires, the plan must include procedures to address family concerns as well as child needs. A service coordinator must be identified, with responsibility for implementing the plan and coordinating with other agencies and persons. Families must be informed of their rights, be a part of the IFSP team, and receive a review of the IFSP at least every 6 months.

In 1998, researchers from SRI and the University of North Carolina at Chapel Hill generated a framework for conceptualizing family outcomes in EI (Bailey et al., 1998). This framework specified two broad types of family outcomes (satisfaction with services, perceived outcomes for families) and eight questions that should be asked in determining family outcomes:

- Does the family see EI as appropriate in making a difference in their child's life?
- Does the family see EI as appropriate in making a difference in their family's life?
- Does the family have a positive view of professionals and the special service system?
- Did EI enable the family to help their child grow, learn, and develop?
- Did EI enhance the family's perceived ability to work with professionals and advocate for services?
- Does the family feel it has a strong support system at the end of EI?
- Did EI help enhance an optimistic view of the future?
- Did EI enhance the family's perceived quality of life?

These questions were used as the conceptual basis for designing a set of family outcome questions included in the interviews conducted as a part of the National Early Intervention Longitudinal Study (NEILS) and therefore for KEILS. This chapter summarizes family outcomes based on interviews conducted with a primary caregiver around the child's third birthday. All families had completed or were about to complete participation in EI. The chapter describes the outcomes reported by families following their experience with EI programs in Kansas.

Instrument and Procedure

This chapter highlights findings on 237 telephone interviews that were conducted at entry and at 36 to 40 months for children and families in KEILS. An interview lasting approximately 40 minutes was conducted with an adult family member. A rigorously trained and quality-monitored survey research unit conducted the interviews using computer-assisted telephone interviewing (CATI), which allows interviewers to read questions and enter responses directly into the computer. CATI technology provided the interviewer with the next appropriate interview question based on the respondent's answers. Designed by the NEILS

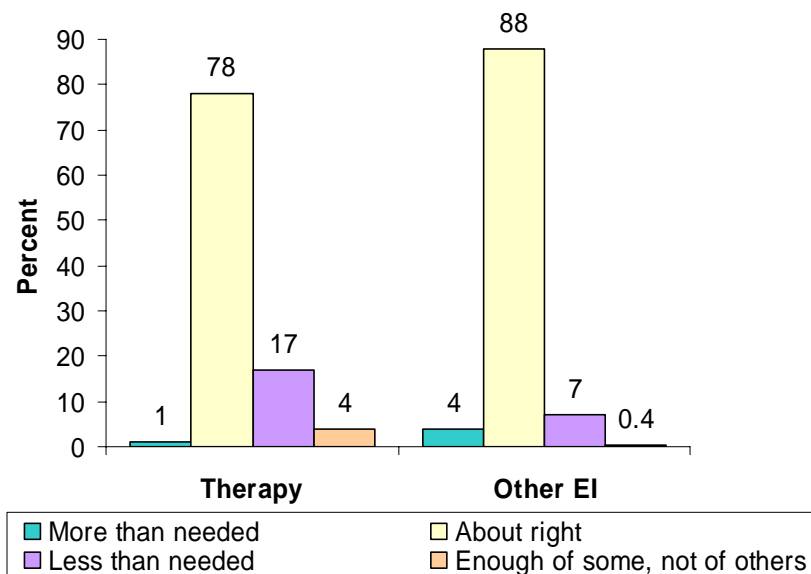
research team, the interview addressed characteristics of the child and family, sought descriptions of the services received, and elicited respondents' perceptions of the effects of EI on themselves and their children. Respondents were given the option to complete the interview in English or in Spanish. Of the 36-month interviews, 2% were conducted in Spanish. A complete copy of the interview and additional information about NEELS can be obtained at www.sri.com/neils/.

Appropriate Services: Do parents see EI as appropriate in making a difference in their child's life?

This question assumes that one important outcome of EI is for parents to feel that the services for their child were appropriate, of high quality, and effective. Nine items addressed parent ratings of (1) the amount of therapy (e.g., physical therapy, occupational therapy, speech-language therapy); (2) the quality of therapy; (3) the amount of EI services other than therapy; (4) the quality of EI services other than therapy; (5) the extent to which services were perceived to be individualized for their child's needs; (6) the number of professionals working with the child; (7) the extent to which professionals communicated with each other; (8) the perceived impact of EI on the child's development; and (9) an evaluation of the child's current life situation. Descriptive statistics for these items and all other items addressed in this report overall and as a function of a set of child and family demographic variables are displayed in Appendix A, and summarized in the paragraphs below.

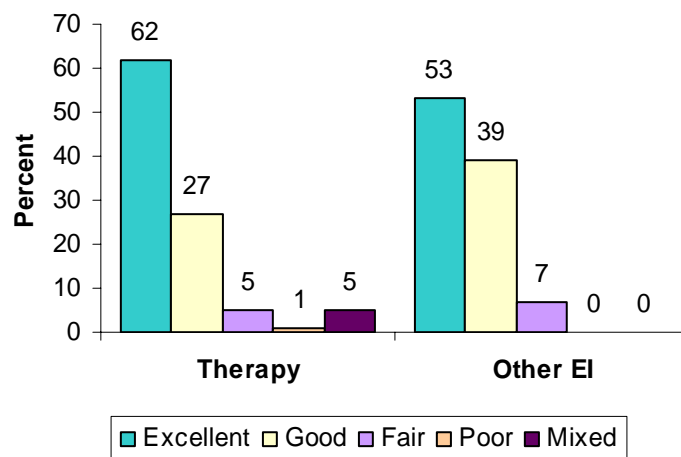
Amount of therapy and EI services (see Figure 6-1). Most parents felt that the amount of therapy (78%) and the amount of EI services other than therapy received over the course of the child's time in EI (88%) were "about right." Some parents felt that the amount of services was less than what their child needed (17% therapy, 7% nontherapy), and a few felt that their child received more therapy (1%) or more EI services (.4%) than were needed.

Figure 6-1. Parent Perception of Amount of Services Provided



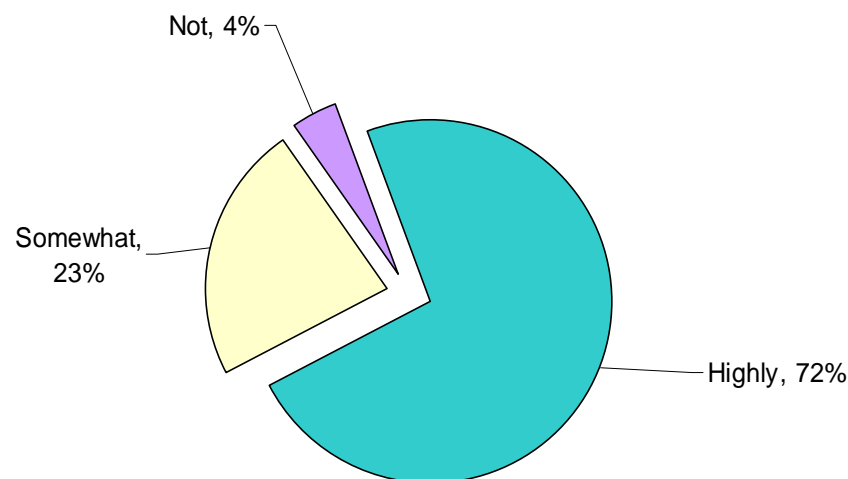
Quality of therapy and EI services (see Figure 6-2). Most parents also had a very positive impression of the quality of services provided over the course of EI. Eighty-nine percent rated the overall quality of therapy services as excellent or good, and 92% rated the overall quality of EI services other than therapy as excellent or good. Only 1% rated therapy quality as poor, whereas 7% rated EI services other than therapy as poor.

Figure 6-2. Parent Rating of quality of Services Provided



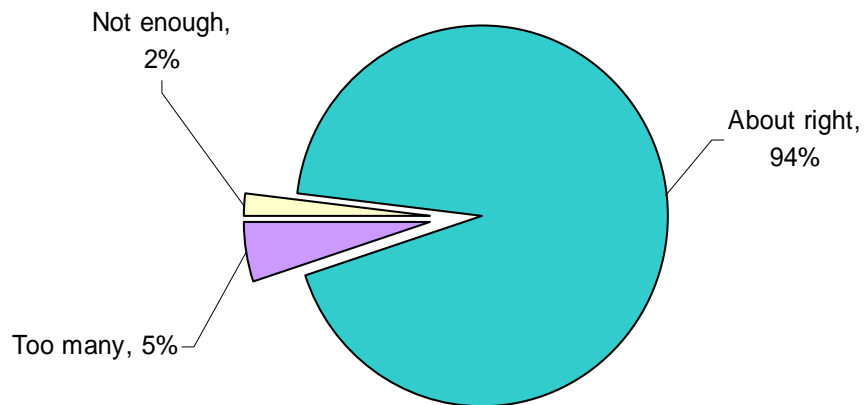
Individualization of services (see Figure 6-3). Nearly three-quarters (72%) of the parents rated their child's services as highly individualized, and another 23% rated services as somewhat individualized. Only 4% rated services as not at all individualized.

Figure 6-3. How Individualized Were Your Child's Services?



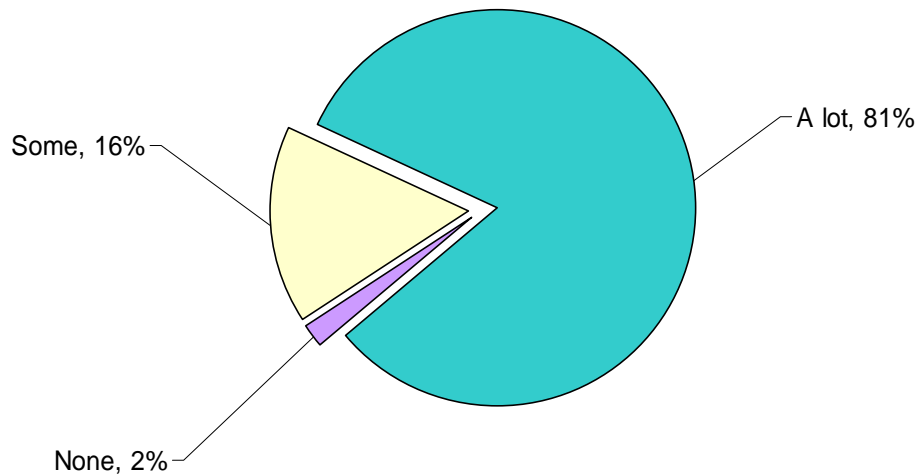
Number of professionals (see Figure 6-4) and interprofessional communication. Most (94%) parents reported that the number of professionals working with their child was about right. Of the remainder, 5% reported too many professionals and 2% not enough. Parents typically rated professionals' communication with each other as excellent (54%) or good (35%). Only 3% reported poor communication among professionals.

Figure 6-4. What Do You Think About the Number of Professionals Who Worked With Your Child?



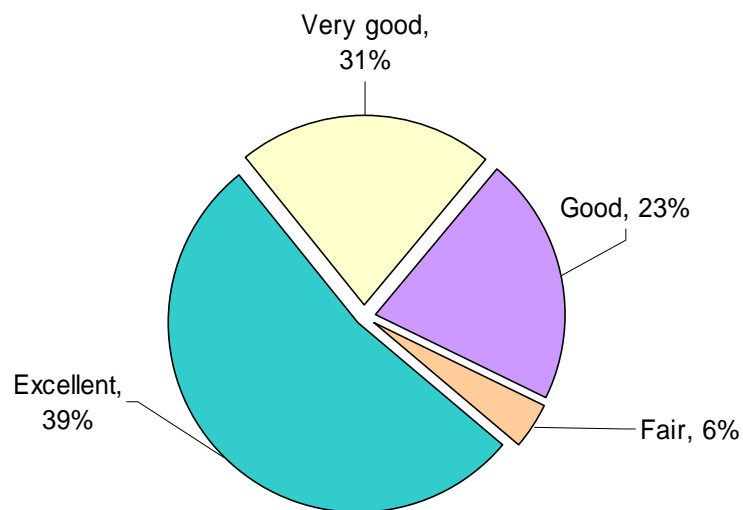
Perceived impact on child (see Figure 6-5) and assessment of child's current life status (see Figure 6-6). Most (81%) parents reported that looking across the entire period of services, EI had "a lot" of impact on their child's development, with another 16% reporting some impact. Only 2% reported no impact of EI on their child's development.

Figure 6-5. Overall, How Much Impact Have Therapy And EI Services Had On Your Child's Development?



Finally, parents were asked, “Thinking about your child’s overall life situation now, would you say it is...?” In response to this question, 75% reported their child’s overall life situation to be excellent or very good. An additional 21% reported their child’s situation to be good, and 4% rated their situation to be fair.

Figure 6-6. Thinking About Your Child's Overall Life Situation Now, Would You Say It Is...?

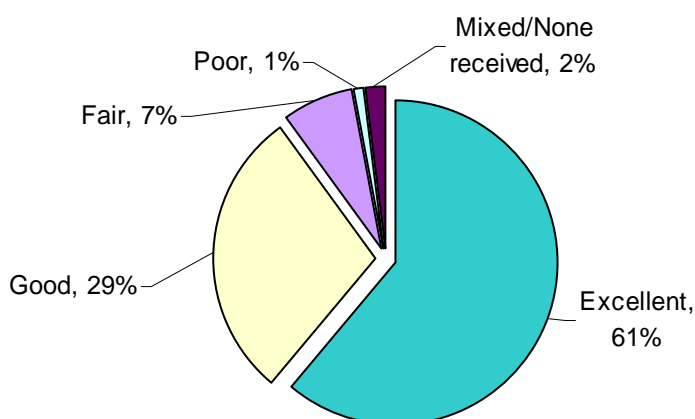


Impact on the Family: Do parents see EI as making a difference in their family's life?

This question assumes that a second broad outcome of EI could be the extent to which parents feel that the services they have received for themselves (as opposed to direct services for their child) were helpful and had an impact on the family. Two questions asked parents to (1) rate the help and information their family had received through EI; and (2) evaluate the extent to which the help and information received has affected their family.

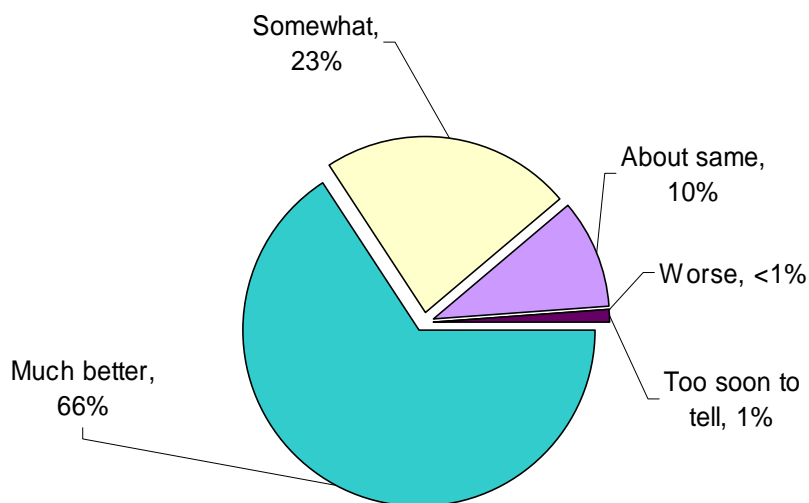
Perceived quality of help or information for the family (see Figure 6-7). As with services for the child, most parents were very positive about the quality of help and information provided for the family, with 90% rating quality of family services as excellent or good. Only 7% rated family services as fair in quality and only 1% as poor.

Figure 6-7. How Would You Rate the Help and Information Your Family Has Received Through EI?



Perceived impact on families (see Figure 6-8). Most parents considered EI to have had a significant impact on their families, reporting their families as much better off (66%) or somewhat better off (23%) as a result of EI. Some parents (10%) reported that their family was about the same, and less than 1% reported that their family was worse off than it had been prior to EI.

Figure 6-8. How Has the Help and Information Received Affected Your Family?



Perceptions of the Service System: Do parents have a positive view of professionals and the special service system?

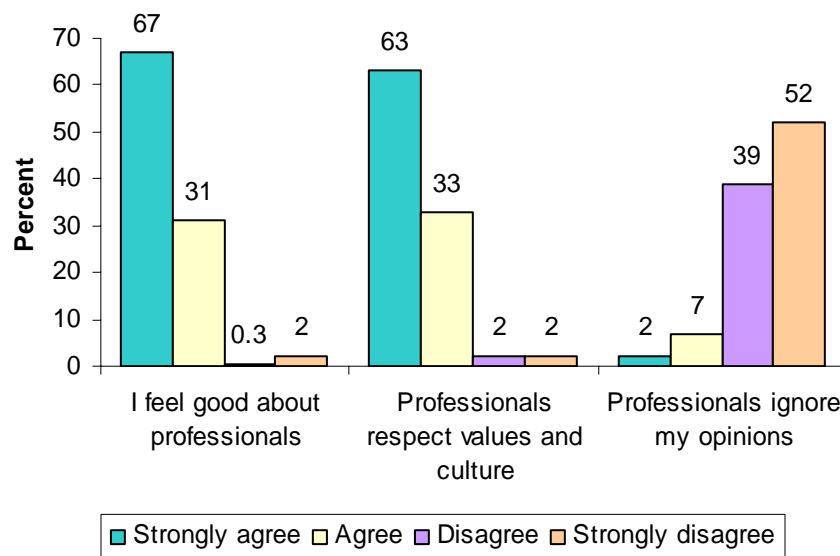
This question assumes that after a period of EI, parents ideally would leave with a positive view of the individuals who provided services for them and the overall system in which those professionals worked. It was also hoped that parents would believe that the system of services was accessible and helpful, and that service providers were supportive, responsive, and respectful. Items addressed the family's (1) overall feelings about the professionals who work in EI; (2) the extent to which professionals respected family values and culture; and (3) whether families felt that professionals ignored their opinions. For each item, a statement was presented (e.g., I have good feelings about the professionals who worked with me and my child.), to which parents indicated one of four ratings: strongly agree, agree, disagree, or strongly disagree (see Figure 6-99).

General feelings about professionals. Parents reported very positive feelings about the professionals working in EI. Almost all (98%) strongly agreed or agreed that they had good feelings about EI professionals, with only 2% disagreeing or strongly disagreeing.

Professionals' respect. Parents were asked to rate the extent to which they felt that professionals working in EI respected their family values and cultural background. As with the first item, almost all (96%) agreed or strongly agreed with this statement.

Ignoring opinions. Parents were also asked to rate the extent to which they felt that EI professionals ignored their opinions. About 9% agreed or strongly agreed with this statement, but most (91%) disagreed or strongly disagreed.

Figure 6-9. Ratings of Early Intervention Professionals

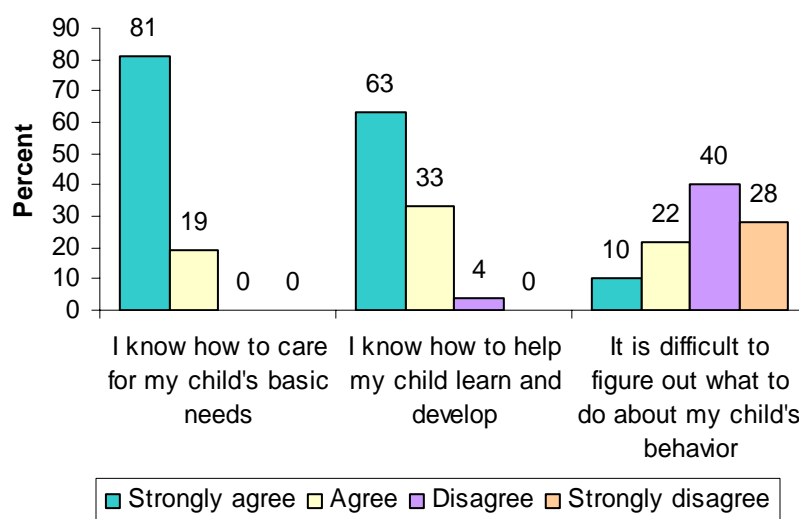


Enhancing Family Capacity: Did EI enable the family to help their child grow, learn, and develop?

Parents play an important role in facilitating their child's development, as exemplified in the ways parents teach their children, arrange the home environment, and promote access to the world around them. In addition, EI ought to help parents be and feel competent as caregivers. Three items asked parents to rate the extent to which they knew how to (1) care for their child's basic needs, like feeding, bathing, and dressing; (2) help their child learn and develop; and (3) figure out what to do about their child's behavior. Each item was presented as a statement (e.g., I know how to care for my child's basic needs.) to which parents indicated one of four ratings: strongly agree, agree, disagree, or strongly disagree (see Figure 6-10).

Caring for child's basic needs. All parents felt that they knew how to care for their child's basic needs, with 81% strongly agreeing with this statement and an additional 19% agreeing with it.

Figure 6-10. Parent Report of Caregiving Knowledge



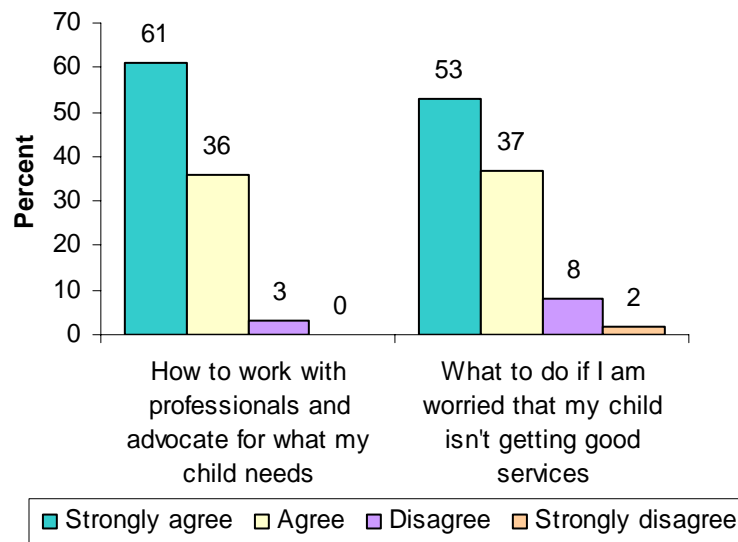
Helping their child learn and develop. Most (96%) parents also felt that they were able to help their child learn and develop, although in comparison with perceived competence in caring for their child's basic needs, fewer provided strong agreement (63%) and more (33%) provided simple agreement. About 4% of the parents disagreed or strongly disagreed with the statement.

Figuring out child's behavior. Parents were asked to rate the extent to which they had a difficult time figuring out what to do about their child's behavior. A number of parents either agreed (22%) or strongly agreed (10%) with this statement, indicating a lower level of perceived competence for dealing with behavior problems than in caring for basic needs or promoting development. However, nearly more than two-thirds of the parents (68%) either disagreed or strongly disagreed with this statement.

Working with the System of Services: Did EI enhance the family's perceived ability to work with professionals and advocate for services?

This question addresses the extent to which family members at the end of their EI experience believe they can negotiate the service system and feel a sense of efficacy when trying to access services for their children. Two questions addressed the parents' perceived ability to (1) work with professionals and advocate for the child's needs; and (2) know what to do if worried that their child was not receiving good services. Each item was presented as a statement (e.g., I know how to work with professionals and advocate for my child's needs.) to which parents indicated one of four ratings: strongly agree, agree, disagree, or strongly disagree (see Figure 6-11).

Figure 6-11. I know...



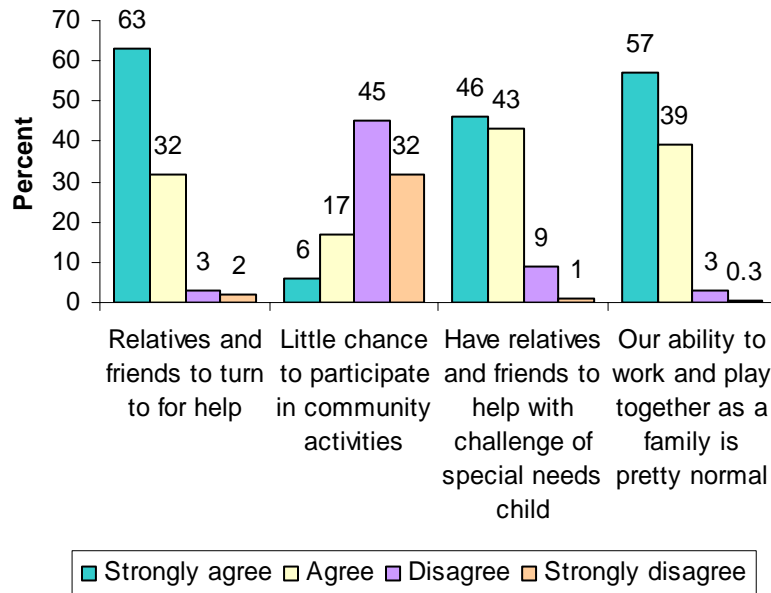
Working with professionals and advocating. One aspect of parent empowerment is feeling competent in working with professionals and advocating for needed services. Most parents either strongly agreed (61%) or agreed (36%) that they know how to work with professionals and advocate for services, with only 3% disagreeing.

Knowing what to do if the child is not receiving needed services. Most parents also strongly agreed (53%) or agreed (37%) that they knew what to do if they did not feel that their child was receiving needed services. Only 10% disagreed or strongly disagreed with this statement.

Supports: Does the family feel it has a strong support system at the end of EI?

This question is based on extensive research suggesting that although professionals provide important specialized services for children and families, the nature and amount of community and social support experienced by a family are highly correlated with successful coping and adaptation. Interview items assessed the extent to which parents (1) had relatives or friends to turn to for help or support when they needed it; (2) could take part in community activities, such as religious, school, or social events; (3) had relatives, friends, or others who helped them deal with challenges faced as a result of their child's special needs; and (4) had a "pretty normal" ability to work and play together as a family. Each item was presented as a statement (e.g., I have relatives or friends to turn to for help or support when I need it.) to which parents indicated one of four ratings: strongly agree, agree, disagree, or strongly disagree (see Figure 6-12).

Figure 6-12. I (we) have...



Friend and relative support. Most parents agreed (32%) or strongly agreed (63%) that they had friends or relatives to whom they could turn for support or help when they needed it. Only 5% disagreed or strongly disagreed with this statement.

Limited opportunities for community activities. Almost a quarter (23%) of the parents agreed or strongly agreed that they had little chance to take part in community activities, such as religious, school, or social events. The remainder disagreed (45%) or strongly disagreed (32%) with this statement.

Relatives and friends to help deal with challenges. Most parents (89%) agreed or strongly agreed that they had relatives or friends to whom they could turn for help in dealing with challenges associated with their child's special needs.

Playing and working together. Most parents (96%) agreed or strongly agreed that their ability to work and play together as a family was pretty normal, even though they had a child with special needs.

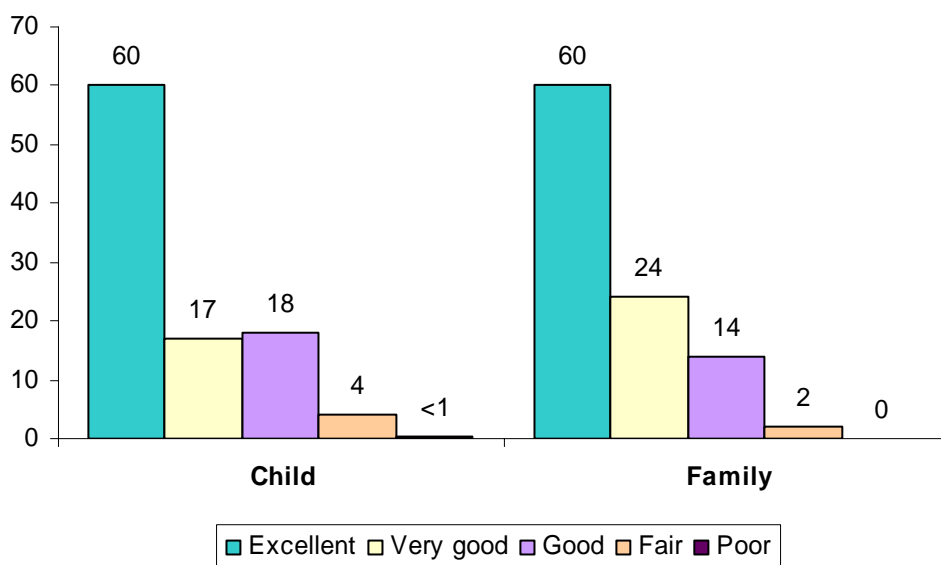
Optimism: Did EI help enhance an optimistic view of the future?

Without adequate support, the challenges inherent in raising a child with a disability could lead to feelings of hopelessness and despair. It is hoped that EI can help families feel increased hope for a positive future and optimism about the possibilities for them and their child. One item addressed this issue directly, asking parents to rate the extent to which EI professionals have made them feel optimistic and hopeful about their child's future, to which respondents indicated one of four ratings: strongly agree, agree, disagree, or strongly disagree. Two additional items asked parents to rate their expectations for what their child's life situation or their family's life situation would be like in the future: excellent, very good, good, fair, or poor.

The extent to which professionals helped families feel hopeful. Most parents either agreed (38%) or strongly agreed (57%) that EI professionals made families feel hopeful about their child's future, with only 6% disagreeing or strongly disagreeing with this statement.

Expectations for child and family future life situation. Families responded similarly to their expectations for their child's future situation or their family's future life situation. Seventy-seven percent of the parents expected their child to have an excellent or very good future life situation and a few more (84%) expected their family's future life situation to be excellent or very good (see Figure 6-13). Only 4% predicted a poor or fair future life for their children, and only 2% predicted a poor or fair future for their families.

Figure 6-13. Looking Toward the Future, Do You Expect That Your Child's/Family's Overall Life Situation Will Be



Quality of Life: Did EI enhance the family's perceived quality of life?

Quality of life is a broad and nebulous construct that encompasses almost the full range of family outcomes. It is a purely subjective phenomenon and could transcend responses to individual questions. To address this issue, a single global item was asked: Thinking about your family's overall life situation now, would you describe it as excellent, very good, good, fair, or poor? About 71% of parents rated their current quality of life as excellent (49%) or very good (22%). Only 5% rated their family's current life situation as fair or poor.

Factors Accounting for Variability in Family Outcomes

The data summarized in the descriptive statistics above present an overall picture of a high degree of satisfaction with EI programs and a perception that the program was successful in achieving many child and family outcomes. However, some families were less satisfied with selected aspects of their program and experienced less positive outcomes. Additional analyses were conducted to identify the families with less positive outcomes.

Family outcomes were examined with respect to the following set of family and child characteristics:

Child characteristics

1. Reason for eligibility (developmental delay, diagnosed condition, at risk)
2. Gender (male, female)
3. Race/ethnicity (white, other)
4. Age at IFSP (birth-younger than 12 months, 12 months-younger than 24 months, 24 months-younger than 36 months)

Family characteristics

1. Maternal education (less than high school, high school/GED, some college, BA/BS or more)
2. Annual household income (less than \$15,000, \$15,000-\$25,000, \$25,000-\$50,000, \$50,000-\$75,000, and more than \$75,000 year)
3. Receipt of public assistance (yes, no)

The data revealed that household income and caregiver education accounted for some variability in family outcomes. Specifically, caregivers from lower income households were more likely to:

- Rate the quality of therapy as fair or poor. Of families with incomes below \$15,000 per year, 22% rated therapy quality as fair or poor, versus no families with income exceeding \$75,000 per year ($p < .001$).

- Indicate that services were less individualized. Of children and families with annual household incomes below \$15,000 per year, 11% found services not to be individualized, compared with none of the families with more than \$75,000 in household income ($p<.001$).
- State that they had little chance to participate in community activities. Nearly half (49%) the families with annual household incomes below \$15,000 stated they had little time to participate in community activities, compared with 0% of their counterparts with higher incomes (above \$75,000 bracket)($p<.01$).
- Rate the child's current life situation as fair or poor. Of families with annual household incomes below \$15,000, 10% rated the child's current life situation as fair or poor, compared with none of the families with incomes exceeding \$75,000 ($p<.001$).
- Disagree that their ability to work and play as a family was normal. Of families with annual household incomes between \$15,000 and \$25,000, 10% disagreed that their ability to work and play as a family was normal, whereas none of their richer (income above \$75,000) counterparts agreed with this statement ($p<.01$).
- Agree that they had difficulty figuring out what to do about the child's problematic behaviors. Of families that had incomes below \$15,000, 45% agreed or strongly agreed that they had difficulties figuring out what to do about the child's problematic behaviors, compared with 5% of those with annual household incomes exceeding \$75,000 ($p<.05$).
- Indicate that they knew what to do if the child is not receiving proper services. Of families that had incomes below \$15,000, 93% agreed or strongly agreed that they knew what to do, relative to 83% of their richer (annual household income exceeding \$75,000) counterparts ($p<.001$).
- State that the effect of EI on the family was such that they were about the same after going through it. Nearly 18% of the families with annual household income below \$15,000 felt EI left them about the same, compared with 5% of those with annual household incomes between \$50,000 and \$75,000 ($p<.01$).
- Agree that EI professionals tended to ignore their opinions. Nearly a third (32%) of families with annual household incomes below \$15,000 agreed or strongly agreed that professionals tended to ignore their opinions compared to just 4% of those families with annual household incomes above \$75,000 ($p<.001$).
- Disagree that EI professionals respected their family values and backgrounds. Of families with annual household incomes below \$15,000, 13% disagreed or strongly disagreed that professionals respected their family's values and backgrounds, compared with none of the richer families (above \$75,000 annual household income) ($p<.001$).
- Agree that professionals' communication with each other was fair or poor. Of families with annual household incomes below \$15,000, 17% felt that professionals' communication was fair or poor, compared with only 3% of families with annual household incomes between \$50,000 and \$75,000 ($p<.001$).
- Want more involvement in service decisions. Of families with incomes between \$15,000 and \$25,000, 11% wanted more involvement, versus no family with household incomes exceeding \$75,000 ($p<.01$).

Caregivers with lower levels of education were more likely to:

- Agree that they had difficulty finding out what to do about the child's problem behaviors. More than half (53%) the families with caregivers that had less than a high school diploma agreed with this statement, compared with 12% of those with an undergraduate college degree or above ($p<.01$).
- Agree that EI professionals tended to ignore their opinions. Nearly a third (32%) of caregivers with less than a high school diploma felt this way, compared with 6% of those with an undergraduate college degree or above ($p<.05$).

Finally, caregivers with children who were younger than 12 months of age at entry were more likely to rate the quality of help given to them by EI professionals as fair or poor. Eleven percent rated the help as fair or poor, compared with 3% of caregivers with children who were older than 24 months at entry ($p<.01$).

Conclusions

This chapter focused on parents' perceptions of the family outcomes of EI at about 36 months.

The study's findings are limited in that they are based only on the experiences of families who participated in the EI system. Families preferring not to participate in Part C EI programs, or whose children were referred but determined not to be eligible, were not included in the study. Families who opted out of Part C services after their initial IFSP are included in the study, and their perceptions are reflected in these data. An additional limitation of the study is that the findings are based on a few questions asked in the context of a telephone survey. More detailed information about family perceptions, especially specific concerns about programs or service providers, could not be captured with this method. A more extensive series of interactions with families would be needed to thoroughly explore the complexity of the family's experiences with the Part C system. One methodological challenge for research on family outcomes is that families typically respond very positively to survey items about their EI experiences (McNaughton, 1994). The positive lens through which families appear to so unanimously view EI is sometimes at odds with other information on how well the system is meeting families' needs (McWilliam, Synder, Harbin, Porter, & Munn, 2000; Montgomery, Parrish, Hebbeler, Spiker, & Cook, 1997). Information from families should be considered as important because it reflects families' perceptions but it does not necessarily indicate that the EI system is operating as effectively as it should. These limitations notwithstanding, a number of conclusions can be drawn about the experiences families have had with EI programs.

Parent Perceptions of Services

Parents in Kansas report a high degree of satisfaction with EI programs and services. Most considered their child's services to have been individualized on the basis of their child's needs and to have been of adequate amount and quality. The number of professionals working with their child was about right, and parents generally felt that the professionals working with their child communicated well with each other.

Likewise, most parents were very satisfied with services provided for the family. At the conclusion of EI most felt good about EI professionals, considering them to have respected their families' values and culture and rarely ignored their opinions. Furthermore, most families agreed that EI professionals made them feel optimistic and hopeful about their child's future.

Parent Perceptions of Outcomes

A second major conclusion is that parents perceived many positive outcomes as a result of EI, both for their child and for their family. Nearly three-fourths reported that EI had “a lot” of impact on their child’s development. Most also reported that their family was better off as a result of the help and information received from EI programs. At the end of EI, most parents felt competent in their parenting role as well as in their ability to work with professionals and advocate for services. Parents generally reported a high degree of support from family members and other individuals or groups. Finally, most parents were hopeful about the future and expected that their child’s overall life situation and that of their family would be excellent or very good.

Areas of Needed Improvement

Although most families reported a high degree of satisfaction with both services and outcomes, selected areas for future study should be noted. For example, parents felt less competent in their ability to figure out what to do about their child’s behavior than in their ability to care for their child’s basic needs or help their child learn and develop. This finding, which is consistent with extensive literature documenting the stress that behavior problems place on families and the challenges families experience in dealing with problem behavior, suggests an area of enhanced service provision in EI, at least for some families. The finding was especially salient for families with lower levels of education and low household income. Second, parents reported less support and participation in community activities than support received from family and friends. This may be a factor associated more generally with the demands and constraints of being a parent of a very young infant, but suggests that EI professionals may need to consider ways to help families access more community supports.

The data also indicate that families felt differently about their EI when their household had limited income. The differences were not large in magnitude, but they appeared consistently across a number of the different outcome items, suggesting that the EI system is working slightly less well for these families. Nonetheless, nearly all families regardless of income, education level, or child characteristics were positive in their impressions of the EI system. Families with limited income were just somewhat less positive than other families, which suggests that more information is needed about how EI in Kansas can better meet the needs of all the families it serves.

CHAPTER 7

FAMILY PERSPECTIVES ON TRANSITIONING OUT OF EARLY INTERVENTION

Federal law stipulates EI services should be provided to “individuals from birth through age two who need EI services” (IDEA97, Part 303, Sub Part A, Section 303.16). States are required to have policies and procedures in place to ensure a smooth transition for children receiving EI services to preschool and/or other appropriate services by the time they turn 3. This chapter addresses the following question:

- How do families rate the help provided to them by EI programs in planning for the transition out of EI after the child turns 3?

Parents were asked questions related to transition experiences at the 36-month interview. As noted in Chapter 1, these interviews were conducted when the child was between 36 and 40 months of age.

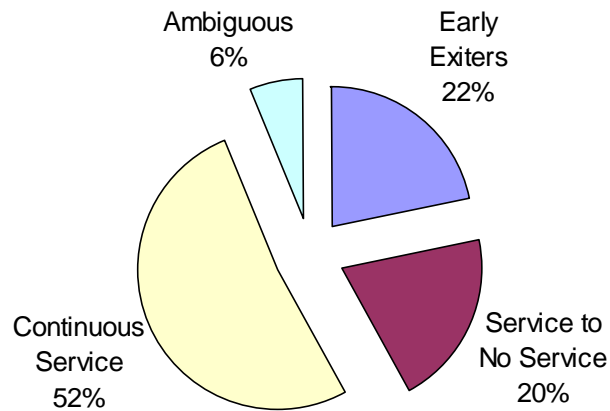
Status at 36 Months

Children were classified into different categories on the basis of their transition experiences from EI. These included:

- Early exiters: Children who left EI before 36 months.
- Service to no service: Children who were receiving EI services but would not receive special services after turning 3.
- Continuous service: Children who would continue to receive services after turning 3.
- Ambiguous: Children for whom the research team was unable to determine whether a change had occurred in service after the children turned 3, given the information available (e.g., information from the program conflicted with information from the family).

Figure 7-1 shows the percentage of children who were classified into each of the above categories. Twenty-two per cent of the children left EI before 36 months, 52% continued to receive services after turning 3, 20% no longer received special services after turning 3, and 6% were ambiguous in that it was unclear whether a change in service and/or receipt of special services had taken place after age 3.

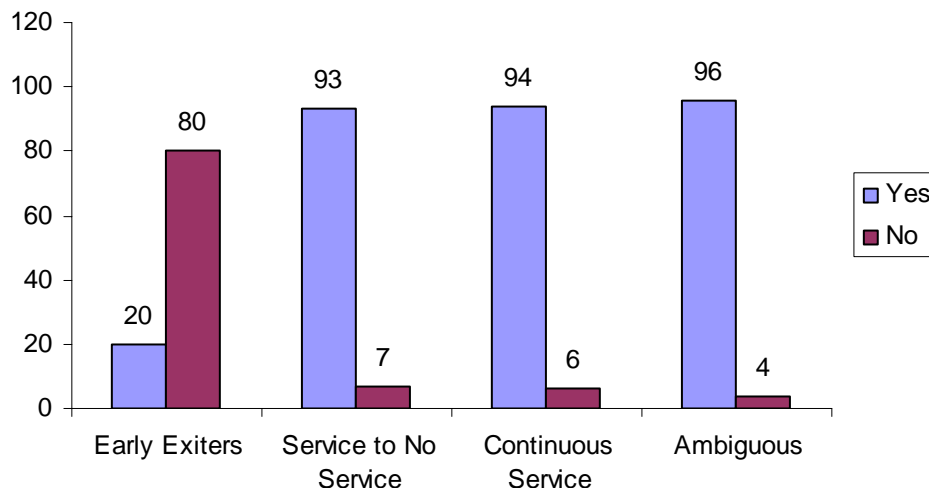
Figure 7-1. Status of Children with Regard to Service Receipt at 36 Months of Age



Transition Experiences

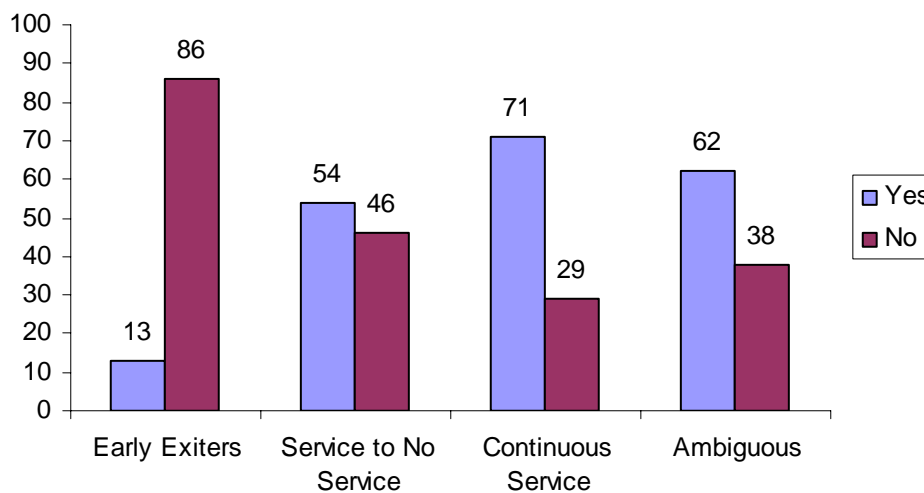
Parents were asked whether their EI program representatives talked to the family about options for preschool or services available when the child turned 3. For those families who reported their children were to receive services after age 3, 94% said that programs had provided this information (see Figure 7-2). Nearly all families whose children were moving from service to no service or whose service status was ambiguous reported that they also received this information. Because the early exiters left EI before the child turned 3, it was not surprising that 80% stated that they did not receive such help from programs.

Figure 7-2. Percentage of Families Who Reported They Were Presented with Preschool or Other Service Options when Child Turned 3, by Child's Service Status at 36 Months



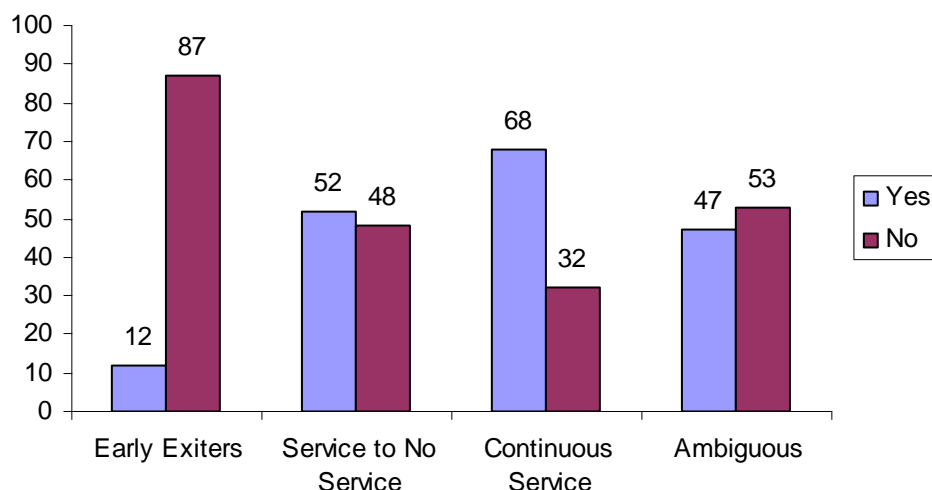
Families were asked whether they were encouraged to visit preschools, centers, or other programs that might serve the child after age 3. Interestingly, a third of the families whose children were to receive services after age 3 responded “no” to this question. They said they were not encouraged to do so (see Figure 7-3). This proportion was even higher for the service to no service group (46%) and for the ambiguous group (38%).

Figure 7-3. Percentage of Families Who Reported that They Were Encouraged to Visit Preschools, Centers, or Other Programs that Might Serve the Child after 3, by the Child’s Service Status at 36 months



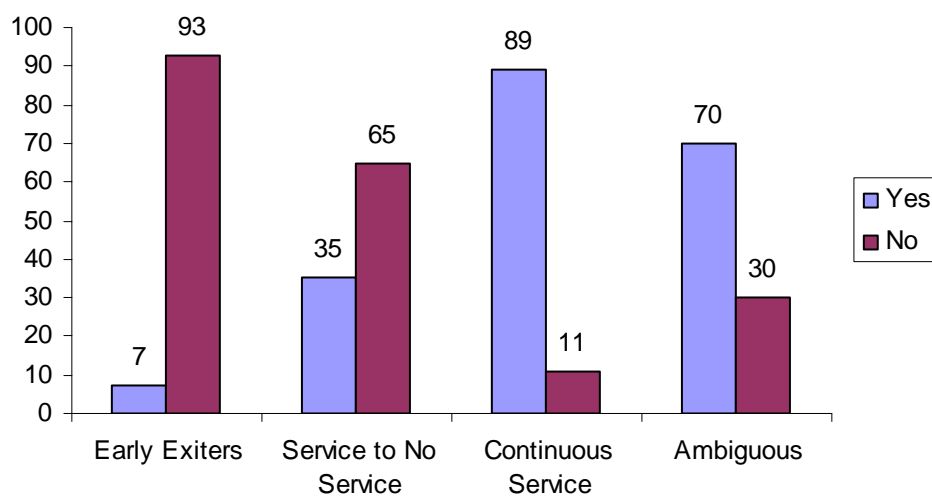
Recognizing the importance of serving children in inclusive settings, caregivers were asked whether the program had suggested options that included the child with children without special needs after the child turned 3. Nearly 70% of the families of children who were to receive special services after 3 reported that the EI program did suggest options that included children without special needs (see Figure 7-4). Alternatively, for about a third of the children, the program did not. The proportion of parents responding “yes” was much smaller for the other three groups, but this could mean the program suggested no options at all, which is almost certainly the case for the children who exited at younger than 36 months of age.

Figure 7-4. Percentage of Families Who Reported that Program Representatives Suggested Options that Included Children Without Special Needs, by Child's Service Status at 36 months



Families asked whether someone from the EI program helped develop a written plan for the services the child would receive after he or she turned 3. Nearly 9 of 10 families of children who were to continue to receive service after age 3 agreed that the programs helped them in this arena, as did 70% of the families whose child's transition status was ambiguous, and a little more than a third (35%) of those families with children who moved from service to no service (see Figure 7-5).

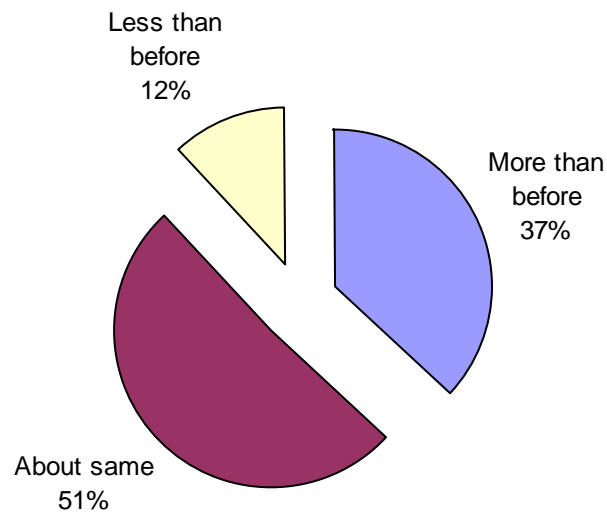
Figure 7-5. Percentage of Children in EI for Whom Families Reported that the EI Program Provided Help with Developing a Written Plan for Services that the Child Might Receive after 3, by Service Status at 36 Months



Amount of Services

Caregivers were asked the amount of services they expected the child to receive after turning 3. For those children who were to receive services after 3 (the continuous group), 51% responded they expected the amount of services to be the same after 3, 37% said the amount would be greater than before, and 12% said the amount would be less than before (see Figure 7-6).

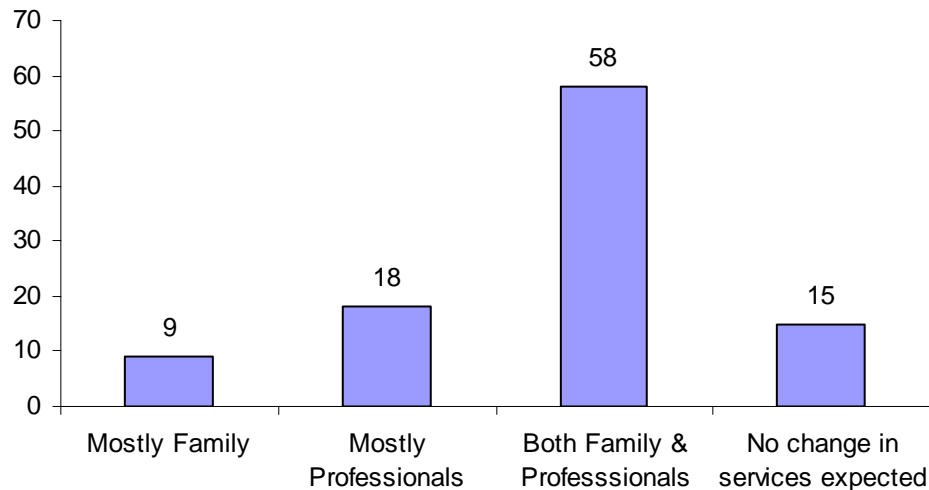
Figure 7-6. Amount of Services Expected after Child Turned 3



Note: Based only on families whose children received services after age 3.

Families were asked about who made the decisions regarding the services the child would receive after 3. Among families who received continuous services after age 3, most (58%) reported that the decision about the *kind* of services the child would receive would be made by the family and the professionals together (see Figure 7-7). When asked about the *amount* of service, 49% indicated the decision was jointly made. Some families (15%) were not asked this question because they reported they did not expect a change in service at 36 months.

Figure 7-7. Families' Perceptions of Who Decided on the Kind of Services Child Should Receive after Turning 3

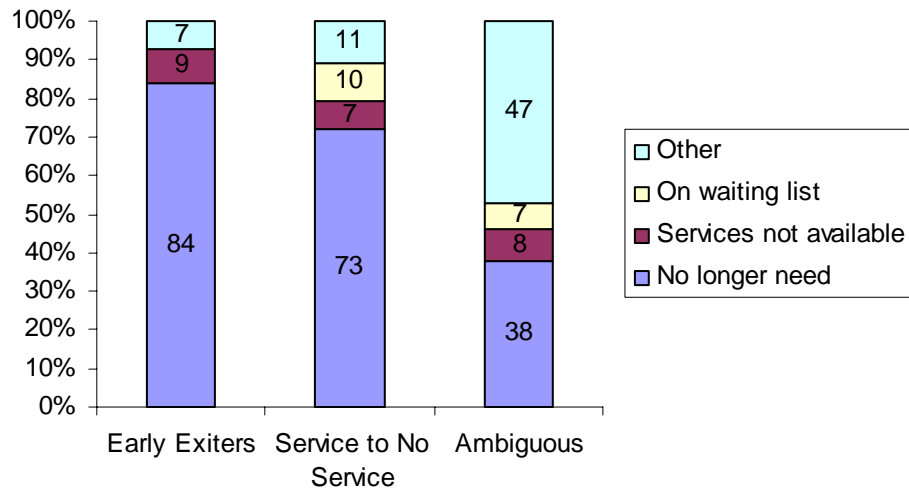


Note: Based only on families whose children received services after age 3.

Overall

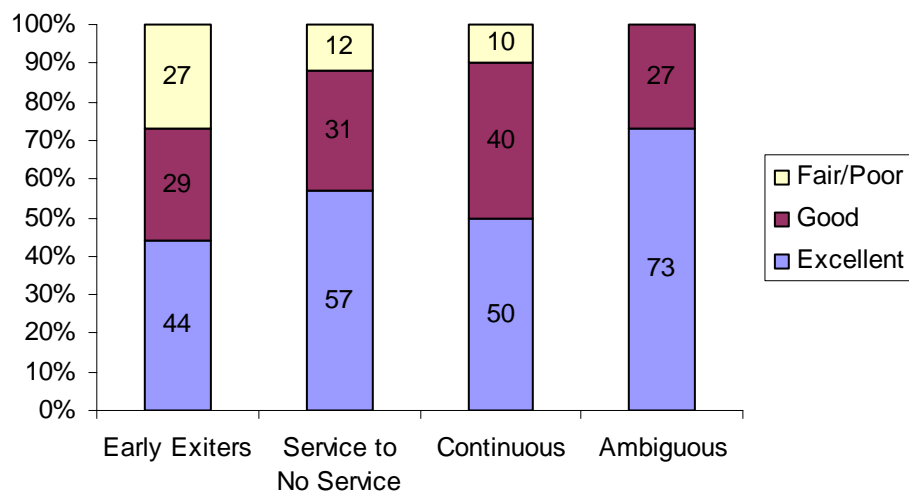
Caregivers who reported the child was not to receive service at 36 months were read a list of possible reasons and asked to indicate which applied. Not surprisingly, 84% of families of the early exiters reported the child no longer needed services (see Figure 7-8). Similarly, 73% of the group that moved from service to no service at 36 months reported the child no longer needed the service. Only 38% of the group for whom service status was ambiguous, said that children left EI because they no longer needed it.

Figure 7-8. Reasons for Not Receiving Services after Age 3



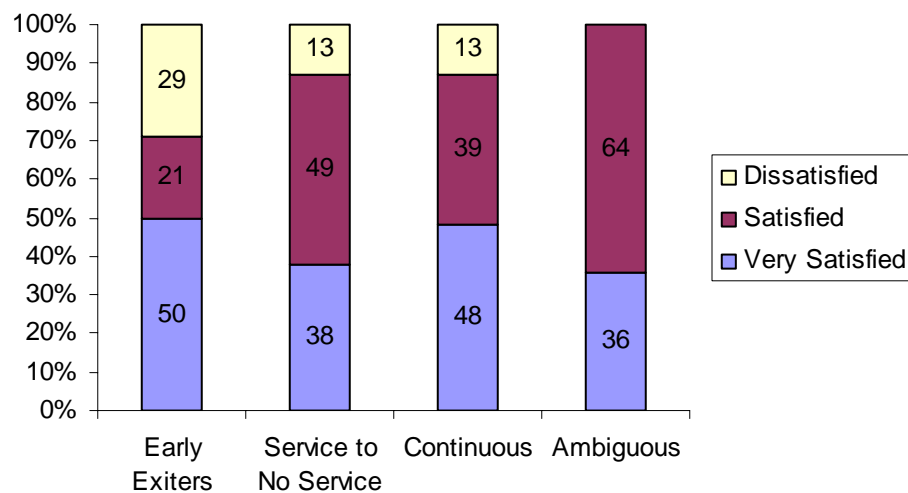
Families were asked to give an overall rating of how well prepared they were for a change in services (see Figure 7-9). About a quarter (27%) of the families whose child left EI before 36 months gave the programs a rating of fair or poor. Only about 1 in 10 of the other two groups gave a fair or poor rating, but that is still a fairly high proportion of families. About half the families (50%) whose child was to receive services after 36 months indicated the preparation provided by the EI program was excellent. None of the families in the ambiguous category rated the programs as fair or poor.

Figure 7-9. Family's Rating of How Well the Program Prepared Family for a Change in Services



Families were also asked how satisfied they were with the overall process of leaving EI. Most families reported they were satisfied or very satisfied (see Figure 7-10) with the process. The families who left EI before 36 months had the highest proportion of very satisfied families (50%) and also the highest percentage of dissatisfied families (29%). This suggests that families within this group were having very different experiences exiting from the system. None of the families whose children's transition status was ambiguous expressed dissatisfaction with this process. Nearly 90% of families with children from the other two groups reported they were satisfied or very satisfied with the process of leaving EI..

Figure 7-10. Family Satisfaction with the Process of Leaving EI, by Child Service Status at 36 months



Conclusions

These findings suggest the following about the process of leaving EI services:

- EI programs in Kansas provided families with various kinds of help in planning for preschool/special education services after the child turns 3.
- For most families, families and professionals made joint decisions about the amount and kind of services that the child would receive after turning 3. Families stated that joint decision making was more frequent concerning the kind of service rather than the amount of service.
- Most families were very pleased with the preparation provided to them and the overall process of leaving the EI system. Among families of children who exited the system before 36 months of age, some reported a very positive experience, but others were far less pleased.

These data provide only a cursory look at the process of leaving EI. The data are limited in that many qualitative issues could not be explored in a telephone survey of the type used in this study. Moreover, many other factors could influence the quality of the transition experience that the study did not examine. Even at the global level used to examine these issues, the findings indicate that transition is not the same experience for all families. This suggests that for some families the system is doing a very good job, but that there is room for improvement with others.

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